



AMERICAN ACADEMY OF  
HOSPICE AND PALLIATIVE MEDICINE

November 6, 2017

Physician-Focused Payment Model Technical Advisory Committee  
c/o U.S. DHHS Asst. Secretary for Planning and Evaluation Office of Health Policy  
200 Independence Avenue S.W.  
Washington, DC 20201  
PTAC@hhs.gov

**Re: *Patient and Caregiver Support for Serious Illness (PACSSI)***

Dear Committee Members,

The American Academy of Hospice and Palliative Medicine (AAHPM) appreciates the Preliminary Review Team's careful review of the Academy's proposal for a physician-focused payment model titled *Patient and Caregiver Support for Serious Illness (PACSSI)*. Our answers to your questions, as transmitted on October 16, are provided on the pages that follow. Should you have further questions or require additional supporting information, please contact Jacqueline M. Kocinski, MPP, AAHPM Director of Health Policy and Government Relations, who can be reached at 847.375.4841 or [jkocinski@aahpm.org](mailto:jkocinski@aahpm.org).

Thank you for your consideration.

Sincerely,

A handwritten signature in dark ink that reads "Janet Bull MD". The signature is written in a cursive, flowing style.

Janet Bull, MD MBA HMDC FAAHPM  
President, AAHPM

**Preliminary Review Team (PRT) Questions from Review of:  
Patient and Caregiver Support for Serious Illness (PACSSI)  
submitted by the American Academy of Hospice and Palliative Medicine (AAHPM)**

**Questions for Submitter**

**Questions about the target population and participant enrollment:**

- 1. The PRT would like to better understand what the composition of the target population is likely to be; for example, what portion of enrollees are expected to have a cancer versus a non-cancer diagnosis, what portion are expected to qualify and use hospice services within 12 months?**

Along with the tremendous growth in specialty palliative care in the United States<sup>1</sup>, there has been a similar growth in the diversity of serious illnesses for which palliative care services are consulted. Similar to the early days of hospice, where cancer represented the majority of patients being served, palliative care's inception in the community grew out of managing patients with advanced malignancies, through outpatient cancer clinics.<sup>2</sup> Demonstration of value across the cancer continuum has led to uptake of palliative care by national oncology societies into guidelines and recommendations.<sup>3</sup> Colleagues in cardiology, pulmonology, nephrology, and others have increasingly called for integration of palliative care into usual care, and populations with distinct illness burdens are being identified, based on their diagnoses.<sup>4</sup> While cancer referrals remain steady, there has been a tremendous increase in non-cancer referrals to palliative care.<sup>5</sup> The same shift occurred years ago in hospice such that, in 2016, cancer diagnosis only made up 27.7% of all hospice diagnoses,<sup>6</sup> while cardiac and circulatory diagnoses accounted for 19.3%, dementia 16.5%, respiratory 10.9%, stroke 8.8%, and other diagnoses 16.7%. The expectation is that cancer diagnosis will account for at least a third of participants in the PACSSI APM, but over time AAHPM believes the shift will be similar to hospice diagnoses with an increasing number of participants with neurological (dementia, Parkinson's), cardiac, respiratory, and stroke

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<sup>1</sup> Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS. The Growth of Palliative Care in U.S. Hospitals: A Status Report. *Journal of palliative medicine*. 2016;19(1):8-15.

<sup>2</sup> Von Roenn JH, Temel J. The integration of palliative care and oncology: the evidence. *Oncology (Williston Park, N.Y.)*. 2011;25(13):1258-1260, 1262, 1264-1255.

<sup>3</sup> Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*. 2017;35(1):96-112.

<sup>4</sup> Dhingra L, Dieckmann NF, Knotkova H, et al. A High-Touch Model of Community-Based Specialist Palliative Care: Latent Class Analysis Identifies Distinct Patient Subgroups. *Journal of pain and symptom management*. 2016;52(2):178-186.

<sup>5</sup> Kamal AH, Swetz KM, Carey EC, et al. Palliative care consultations in patients with cancer: a mayo clinic 5-year review. *Journal of oncology practice*. 2011;7(1):48-53.

<sup>6</sup> NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, September 2017. [https://www.nhpc.org/sites/default/files/public/Statistics\\_Research/2016\\_Facts\\_Figures.pdf](https://www.nhpc.org/sites/default/files/public/Statistics_Research/2016_Facts_Figures.pdf). Accessed on November 4, 2017

diagnoses. In addition, mortality rates from cancer continue to decrease, which will also contribute to the increase in non-cancer diagnosis.<sup>7</sup>

The Four Seasons Compassion for Life Center for Medicare and Medicaid Innovation (CMMI) Project titled “Increasing Patient and System Value with Community-Based Palliative Care” was conducted in a retirement community where 25% of the population is over 65 years old, and dementia was the number one referral diagnosis.<sup>8</sup> Greater heterogeneity is now being seen in community palliative care programs; for example, a home-based palliative care program conducted within an Accountable Care Organization had 80% non-cancer and only 20% with a cancer diagnosis,<sup>9</sup> and a large community-based palliative care program in New York demonstrated congestive heart failure as the top diagnosis, (36%) followed by cancer (30%).<sup>10</sup>

The expectation is that approximately 45-50% of participants will utilize hospice services in a 12-month period. In the CMMI project cited above, of the 5787 enrollees, 45% have transitioned to hospice care. Other demonstrations show a similar to higher transition rate within a 12-month period.<sup>11, 12</sup>

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<sup>7</sup> Siegel RL, Miller KD, Jemal A. Cancer statistics, 2016. *CA: a cancer journal for clinicians*. 2016;66(1):7-30.

<sup>8</sup> Bull J, Kamal AH, Harker M, et al. Tracking Patients in Community-Based Palliative Care through the Centers for Medicare & Medicaid Services Healthcare Innovation Project. *Journal of palliative medicine*. Nov 2017. (in print)

<sup>9</sup> Lustbader D, Mudra M, Romano C, et al. The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization. *Journal of palliative medicine*. 2016.

<sup>10</sup> Dhinrgra, L et al A High-Touch Model of Community-Based Specialist Palliative Care: Latent Class Analysis Identifies Distinct Patient Subgroups, *Journal of pain and symptom management*, Volume 52, Issue 2, August 2016, Pages 178-186

<sup>11</sup> California Healthcare Foundation Up Close: A Field Guide to Palliative Care Retrieved from: <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/PDF%20U/PDF%20UpCloseFieldGuidePalliative.pdf>

<sup>12</sup> Lustbader D, Mudra M, Romano C, et al. The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization. *Journal of palliative medicine*. 2016.

- 2. Please describe how patients would enter the program, including:**
- a. What is the source of patients / how do patients find their way into the project? Are patients referred to the program by their current providers or actively recruited independent of their current providers? How?**

Patients can be enrolled by palliative care teams (PCTs) participating in the PACSSI model when they are identified to meet eligibility criteria – a combination of a serious illness diagnosis, functional decline, and health care utilization – outlined in Table 1 of our proposal.

To facilitate patient identification and referral, PCTs will develop outreach efforts in their community to educate providers, health systems and health plans on PACSSI eligibility criteria and patient identification, and to describe the benefits of PACSSI services, both to patients and caregivers and to their organizations. Patients with serious illness and their caregivers will receive 24/7 support where they live to manage physical, emotional, spiritual, and practical needs. Primary care and specialty care providers will receive expert help from specialty PCTs to manage their most seriously ill patients, whose needs (particularly in the community) often challenge and strain the resources of busy practices. And health systems and health plans will be able to deliver palliative care services to seriously ill patients and beneficiaries where they live, through PCTs that are accountable for both quality and cost of care.

Aided by such outreach, we anticipate that eligible patients will be identified and/or referred by one or more of the following:

- Current providers of primary or specialty care, during the course of evaluation and/or ongoing management;
- Emergency department or hospital providers, during the course of emergency or hospital care;
- Skilled nursing, assisted living, or long term-care providers, either at initiation or during the course of care delivery;
- Home health providers, either at initial assessment or during the course of home health delivery;
- Hospice providers, either at initial assessment if the patient is found to not be hospice eligible, or when a patient becomes ineligible and is discharged, or elects to revoke the hospice benefit;
- Integrated health systems, Accountable Care Organization (ACOs), health plans or other entities that are accountable for patients' health care services across care settings, through use of available data sources that can support PACSSI eligibility;
- Patients or family caregivers who self-identify the need for palliative care services

Data to support an individual patient's PACSSI eligibility (diagnosis, functional decline and utilization) may be obtained from a variety of sources, including (but not limited to): routine clinical assessments of patients and caregivers; clinician "trigger" mechanisms or screening tools engaged at the point of care; electronic health record data; practice, hospital or health system administrative data; and claims data. Numerous programs today are using different combinations of these mechanisms to identify patients and caregivers

with unmet palliative care needs in order to identify patients for recruitment into community palliative care programs. We anticipate that some PCTs would also take advantage of such mechanisms for recruitment, and that PACSSI participation would enable wider implementation, testing, validation and refinement of these tools.

**b. How will each patient’s primary and specialty care providers be involved in the patient’s decision to enroll in the PACSII model? Are these clinicians informed that the patient is being recruited into the program? Is the patient told that their primary care and specialty physicians are aware of the referral / recruitment?**

We anticipate that a significant number of patients enrolled with PACSSI-participating PCTs will be identified by their primary care or specialty providers, through some combination of mechanisms described under 2a above. In these cases, the primary providers will be directly involved in the decision to enroll, by recommending and referring to a PACSSI-participating PCT.

For patients referred to PACSSI-participating PCTs by a mechanism other than their primary or specialty care providers, the PACSSI enrollment process will prompt communication with the patient’s primary and specialty care providers. One required element of this process (listed on page 6 of our proposal) is that patients will “agree to work with the PCT to develop a care plan, in coordination with primary care and/or primary treating providers”. This requirement is designed to engage patient, primary care and/or primary treating providers with the PCT together, to think holistically about the supports and services needed to meet patient and caregiver needs. And as noted in the response to question 19, PCTs will be responsible for informing primary and specialty providers of their patients’ participation in PACSSI.

Note also that that the service requirements for PACSSI participation (p. 7, bottom) require PCTs to do the following:

- Develop a coordinated care plan with input from all of the patient’s physicians and providers that is consistent with the patient’s care goals.
- Communicate with the patient’s other physicians and providers on an ongoing basis to ensure care is being delivered consistent with the care plan and to update the care plan as conditions warrant.

These service requirements will facilitate communication with primary care and/or primary treating providers not only, on enrollment (during care plan development), but also throughout the course of care. This will allow primary care and specialty care providers to be involved in decisions both to enroll and to continue in care with a PACSSI-participating palliative care team. Note that PACSSI eligibility and tier assignment will be re-assessed at least every six months, requiring PCTs to document and update serious illness diagnosis and functional status. These reassessments will prompt additional coordination and collaboration with primary and specialty care providers to understand the nature of illness progression and treatment outcomes, to ensure that PCT services are still needed, and still appropriately tiered.

**3. How are patients educated on the implications of enrolling in the program for the patient and for the patients' primary and specialty care providers; i.e., that primary and specialty providers can no longer be able to bill for care management, and that the PCT is their "primary provider of care management services and palliative care services?" Are patients provided the opportunity to discuss their enrollment with their primary care and specialty care providers prior to enrollment?**

For any patient determined to be eligible for PACSSI, the PCT would be responsible for following clearly articulated procedures for informing patients about:

- The PACSSI model overall, including:
  - The model's goals to:
    - Improve the availability of high-quality, interdisciplinary palliative care for patients with serious illness who are not eligible or who have not elected hospice care, and their caregivers, and allow broad participation in a new payment model for interdisciplinary PCTs serving patients and caregivers in all settings and all geographies;
    - Improve the quality of care such patients receive, as well as patients' and caregivers' quality of life; and
    - Achieve savings for the Medicare program for those patients with serious illness who are eligible to participate in the model.
  - The benefits and services offered under the model
  - The model's payment reforms and incentives. This includes information that providers will be compensated monthly to provide palliative care services, and that providers may be additionally compensated or penalized based on achieving certain targets for shared savings which could be driven in part by patients' decisions to forego curative intent therapy.
- PCT responsibilities under the model
- Patient and family responsibilities (including working with the PCT to develop a care plan in coordination with primary care and/or primary treating providers and adhering to the care plan)
- Limitations regarding receipt of chronic care management (CCM) and complex chronic care management (CCCM) services
- The right to disenroll from participation in PACSSI at any time.

We note that, under current Medicare fee-for-service (FFS) rules, CCM and CCCM have similar restrictions allowing only one practitioner to be paid for these services for a given patient for a given month, and also require beneficiary consent. We believe that such a restriction is necessary to ensure integrity of payments under the Medicare program, but more importantly to ensure that PCTs can establish a strong and clear care management relationship with patients. Further, we believe that such restriction does not limit patient choice any more than it is limited under the Medicare FFS program. We note that patient consent is required for the delivery of CCM and CCCM codes, and that consent requires that patients be informed that only one practitioner can furnish and be paid for CCM services during a calendar month.

Following notification of the above elements of PACSSI participation, patients would consent to participation in PACSSI prior to effectuating enrollment, including the following elements of PACSSI participation:

- Designating the PCT as the patient’s primary provider of care management services and palliative care services, in coordination with primary care and/or primary treating providers;
- Working with the PCT to develop a care plan that highlights patient engagement and shared decision-making in coordination with primary care and/or primary treating providers; and
- Adhering to the care plan to the best of the patient’s and caregiver’s ability as long as the PCT meets its commitments to deliver quality care and support to the patient and caregiver.

Patients would also be offered the opportunity to consult with their primary and specialty care providers prior to effectuating their enrollment, although we recognize that not all patients would choose to do so.

AAHPM believes that this formalized notification and consent process will enable potential enrollees to determine if participation in PACSSI is appropriate for their needs. AAHPM acknowledges that patients whose care is well managed by their existing providers may not be appropriate for the PACSSI model. For these patients, PCTs may continue to provide and bill for services under Medicare FFS consistent with current coverage and payment rules.

4. Page 5 of the proposal, refers to, “\* Serious chronic conditions as described in the Dartmouth Atlas: [http://www.dartmouthatlas.org/downloads/methods/chronic\\_disease\\_codes\\_2008.pdf](http://www.dartmouthatlas.org/downloads/methods/chronic_disease_codes_2008.pdf)” (emphasis added). However, we do not find reference to SERIOUS chronic illnesses at this site. (Emphasis added) Do you mean the nine chronic conditions used in The Dartmouth Atlas of Health Care 2008?

Yes, we are referring to those nine chronic conditions used in the Dartmouth Atlas. Thank you for the opportunity to clarify the information in the proposal.

Diagnosis of serious illness is one of the three criteria – along with function and health care utilization – that AAHPM proposes for determination of PACSSI eligibility (see Table 1, p. 4). We propose that patients can meet the serious illness criterion in one of two ways (see Table 2, p. 6): either by diagnosis with one of the serious illnesses listed in Option 1; or by diagnosis with three or more of the chronic illnesses used in the Dartmouth Atlas of Health Care in 2008.

**5. Page 2 of the proposal states, “Internal analysis of available data suggests that up to 5 percent (2.75 million) of Medicare beneficiaries could benefit from palliative care services each year.” Could you provide the PRT with a copy of this analysis?**

There is currently no single, widely accepted and evidence-based methodology to define the population of patients who could benefit from palliative care. As a result, AAHPM derived an estimate using several sources, including the following:

- Most recently available Medicare data showing that a total of 2,148,766 Medicare beneficiaries died in 2014, and that the number of Medicare deaths is growing each year;<sup>13</sup>
- Estimates of the percentage of deaths that could benefit from palliative care services, that range from 69% to 82%;<sup>14</sup>
- Evidence showing that there are many older adults with serious illness who are expected to live longer than 12 months<sup>15</sup>, which will add substantially to the number of Medicare beneficiaries who can benefit from palliative care services;

Our estimate acknowledges an incomplete methodology currently available to define the population that – and, more importantly, identify individual beneficiaries who – can benefit from palliative care services. Evidence and experience from a PACSSI demonstration would measurably improve this understanding, as well as inform future research and policy making regarding value-based care for patients with serious illness and their caregivers.

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<sup>13</sup> [https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMSProgramStatistics/2014/Downloads/MDCR\\_ENROLL\\_AB/2014\\_CPS\\_MDCR\\_ENROLL\\_AB\\_33.pdf](https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/CMSProgramStatistics/2014/Downloads/MDCR_ENROLL_AB/2014_CPS_MDCR_ENROLL_AB_33.pdf)

<sup>14</sup> Fliss EM, Bausewein C, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Med* 2014;28(1):49-58

<sup>15</sup> Kelley AS, Covinsky KE, Ritchie CS. Identifying Older Adults with Serious Illness: A Critical Step toward Improving the Value of Health Care. *Health Serv Res* 52:1, Part 1 (Feb 2017).

## Question about the composition of the PCTs:

### 6. Page 40 of the proposal (Appendix 7) states:

*“PCTs would be able to organize themselves and determine the appropriate level of representation across multiple disciplines, including physicians, nurses (including advanced practice nurses), social workers, spiritual care providers, physician assistants, pharmacists, counselors and others, as needed and appropriate to address the needs of the local patient community.”*

**Are there any minimum requirements or standards for the composition of the PCT? Will / must they all include a physician? Will / must they all include a nurse? Will one or more of the members be required to be certified in palliative care?**

Yes, PACSSI teams must adhere to standards and discipline representation requirements for every palliative care team as laid out in the Clinical Practice Guidelines for Quality Palliative Care (Third Edition)<sup>16</sup>. Palliative care, by definition, requires an interdisciplinary team. A physician must be part of the team, along with a nurse, a social worker, and a spiritual care provider. Other disciplines as necessary to provide the best care for the patient and family may also be included on the PCT. These may include a pharmacist, psychologist, nurse aide, volunteer, and bereavement specialist. At a minimum, one of the core interdisciplinary team members must have certification in palliative care to support specialty level practice.

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<sup>16</sup> [https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf), accessed November 4, 2017.

## Questions about the scope of the PCTs' work:

7. Page 8 of the proposal states that the PCTs would be required to “*educate the patient and caregiver about the patient’s health conditions and the normal progression of those conditions...*” (Emphasis added). What are the sources of clinical expertise available to the PCTs such that the PCTs can accurately discuss with the patients the “normal progression” of their conditions? Will the PCTs do this independent of the patient’s primary care and specialty providers?

Physicians in general are uncomfortable in sharing prognosis with patients. For example, oncologists over prognosticate by a factor of five and, even if patients asked for prognostication, only 37% would give honest disclosure.<sup>17</sup> However, research has demonstrated that patients often want to know what their prognosis is. In a study of 322 patient/family dyads, people with cancer who understood their terminal diagnosis had better mental health, better quality of death, and their caregivers had better bereavement adjustment.<sup>18</sup> Educating family and patients on prognosis helps in enhancing informed consent around treatment options and helps patients focus on how they want to spend the remainder of their days.

Palliative care specialists receive training in prognostication, which is an important piece of the skillset required by a PCT. When end-of-life conversations are held, use of ICU, ventilators, chemotherapy, and CPR are all reduced while hospice transition and hospice length of stay is increased.<sup>19</sup> In addition, systematic review of both cancer<sup>20</sup> and non-cancer diagnosis<sup>21</sup> find that when certain factors are present – which include a poor performance status, advanced age, malnutrition, organ dysfunction, and hospitalization for acute decompensation – treatment did not improve survival. Trajectories of functional decline have been identified for cancer, organ failure, and frailty; hence, educating patients and families about their normal progression of disease is evidence based.<sup>22</sup> While disease specific sources for prognostication in cardiac, pulmonary, dementia, renal, and liver

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<sup>17</sup> Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Annals of internal medicine*. 2001;134(12):1096-1105.

<sup>18</sup> Ray A, Block SD, Friedlander RJ, Zhang B, Maciejewski PK, Prigerson HG. Peaceful awareness in patients with advanced cancer. *Journal of palliative medicine*. 2006;9(6):1359-1368.

<sup>19</sup> Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama*. 2008;300(14):1665-1673.

<sup>20</sup> Salpeter SR, Malter DS, Luo EJ, Lin AY, Stuart B. Systematic review of cancer presentations with a median survival of six months or less. *Journal of palliative medicine*. 2012;15(2):175-185.

<sup>21</sup> Salpeter SR, Luo EJ, Malter DS, Stuart B. Systematic review of noncancer presentations with a median survival of 6 months or less. *The American journal of medicine*. 2012;125(5):512.e511-516.

<sup>22</sup> Lunney, JR, Patterns of Functional Decline. *JAMA* 2003 289 (18) 2397-92

failure<sup>23,24,25,26,27</sup> are more predictive of a 2-3 year prognosis, a shorter prognosis occurs when combined with functional, nutritional, and cognitive decline.<sup>28</sup> In the outpatient cancer population, Palliative Performance Scale (PPS) and/or Eastern Cooperative Oncology Group (ECOG) Scale of Performance Status scores are predictive of mortality.<sup>29</sup>

PCTs act as consultants to both primary care and specialty physicians, and they coordinate and collaborate with these treating physicians on understanding the benefits and burdens of different treatment options. Prognostic information is better understood when clinicians are working together. Information concerning prognosis is shared after this collaboration occurs, in a sensitive manner that respects and honors the patient's and family's values and preferences.

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<sup>23</sup> Celli BR, Cote CG, Marin JM, et al. The body-mass index, airflow obstruction, dyspnea, and exercise capacity index in chronic obstructive pulmonary disease. *The New England journal of medicine*. 2004;350(10):1005-1012

<sup>24</sup> Mitchell SL, Kiely DK, Hamel MB, Park PS, Morris JN, Fries BE. Estimating prognosis for nursing home residents with advanced dementia. *Jama*. 2004;291(22):2734-2740.

<sup>25</sup> Setoguchi S, Stevenson LW, Schneeweiss S. Repeated hospitalizations predict mortality in the community population with heart failure. *American heart journal*. 2007;154(2):260-266.

<sup>26</sup> Hudson M, Weisbord S, Arnold RM. Prognostication in patients receiving dialysis #191. *Journal of palliative medicine*. 2007;10(6):1402-1403.

<sup>27</sup> Kamath PS, Wiesner RH, Malinchoc M, et al. A model to predict survival in patients with end-stage liver disease. *Hepatology (Baltimore, Md.)*. 2001;33(2):464-470.

<sup>28</sup> Salpeter SR, Luo EJ, Malter DS, Stuart B. Systematic review of noncancer presentations with a median survival of 6 months or less. *The American journal of medicine*. 2012;125(5):512.e511-516.

<sup>29</sup> Jang RW, Caraiscos VB, Swami N, et al. Simple prognostic model for patients with advanced cancer based on performance status. *Journal of oncology practice*. 2014;10(5):e335-341.

**8. Please describe more fully what palliative care services the PCTs will deliver themselves, as opposed to coordinating the delivery of palliative care by other providers caring for the patients. What “hands on” clinical services (if any) will PCTs provide to their patients?**

**For example, will PCTs:**

- **Conduct physical examination of the patient?**
- **Take a health history of the patient?**
- **Prescribe medication(s) to address; e.g., pain, nausea, dyspnea?**
- **Prescribe DME**
- **Prescribe physical therapy or occupational therapy?**
- **Prescribe nursing interventions to be followed by caregivers and home health personnel**
- **Perform any nursing interventions such as medication administration**
- **Other?**

The PCT will provide a comprehensive interdisciplinary assessment consistent with the Clinical Practice Guidelines Domains<sup>30</sup> of palliative care. These eight domains include structure and process, (interdisciplinary team), physical, psychological, social, spiritual, cultural, care at the end of life, and ethical and legal aspects of care. These guidelines from the National Consensus Project for Quality Palliative Care delineate optimal practice and serve to standardize palliative care. The “hands on” services include a thorough history, physical exam, and high complexity medical decision-making given the nature of the serious illness and the functional impairment. Thorough symptom assessments are completed using validated screening tools, and medications that promote symptom control are routinely prescribed. Functional assessments are performed as part of the initial visit and appropriate assistance devices (wheelchair, cane, etc.) that promote the well-being and safety of the patient are prescribed. The addition of therapies (physical, occupational, speech, home health) are need-based, as are the provision of advanced psychological or psychiatric support. These therapies are ordered by the PCT along with orders for Durable Medical Equipment.

Shared decision-making, a key component of palliative care, revolves around understanding the patient’s values and preferences, providing education that is understandable, and working together to align treatments and therapies that can be incorporated into a care plan that aligns with a patient’s goals. Goal-directed care, which includes advance care planning, is a component of palliative care. Suffering may occur in the physical, psychological, or spiritual domains. Identifying causes of suffering and aligning treatment and support is common around social and spiritual determinants of care. PCTs will frequently make referrals to other community programs that may provide support, such as Meals on Wheels, Adult Day Care, Medicaid assistance, transportation services, and prescription assistance programs, and collaborate with representatives of the patient’s faith or spiritual origin.

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<sup>30</sup> [https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf), accessed November 4, 2017.

## Questions about quality and quality measurement:

9. The PRT notes that aspects of quality to be measured are contained in pages 11-13 of the proposal, but is unclear about how these concepts are to be measured. Please send to the PRT the exact measures (or other descriptive information such as the measure steward, links to their specifications) for use in this model.

When designing accountability for quality in this model, AAHPM's intention was to strike a balance between acknowledging the significant gaps in where the development and implementation of palliative care quality measures is now and driving toward where we expect to be in a few years. If we used only established measures of palliative care quality exactly as they are currently specified, we would be limited mostly to process measures for narrowly defined subgroups of the seriously ill population, for example, only those with advanced cancer, receiving specialty palliative care consultation in a hospital or enrolled in hospice. On the other hand, if we leapfrogged to our desired future and outpaced quality development in our field, we would risk ineffective measures, unintended consequences and excessive burdens on participating providers.

Measuring What Matters<sup>31</sup>, an expert consensus project convened by AAHPM and the Hospice and Palliative Nurses Association (HPNA), identified serious gaps in the measures available for palliative care quality improvement, including a lack of adequate measures to address the social, cultural and end-of-life domains of palliative care (as defined in the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, 3rd Edition, 2013), and the need for a denominator that captures the population of seriously ill patients appropriate for palliative care across a broad range of diagnoses and healthcare settings<sup>32,33</sup>. A recent survey of AAHPM and HPNA members revealed major ongoing challenges for quality improvement, including an inability to extract measures that matter automatically from the dozens of electronic health record systems currently in use<sup>34</sup>.

Although measures based on patient reported outcomes (PROs) are desirable, implementing PROs is particularly challenging in the seriously ill population receiving palliative care and hospice, where cognitive and physical impairments are common and the underlying illness frequently advances, causing higher symptom burdens, increasing impairment and progression toward death, even with optimal treatment. To date, the most useful outcome measures have been those based on post-death surveys of bereaved family members regarding their experience of hospice care. The difficulties of implementing PRO-

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<sup>31</sup> <http://aahpm.org/quality/measuring-what-matters>

<sup>32</sup> Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., Mcmillan, S. C., Herr, K., Rotella, J.D., Casarett, D. J. (2015). Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care From the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain and Symptom Management*, 49(4), 773-781. doi:10.1016/j.jpainsymman.2015.01.012

<sup>33</sup> [https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2017/04/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf), accessed November 4, 2017.

<sup>34</sup> Lindley, L., Rotella, J., Ast, K., Matzo, M., & Kamal, A. (2017). The Quality Improvement Environment: Results of the 2016 AAHPM/HPNA Membership Needs Assessment Survey. *Journal of Pain and Symptom Management*, 54(5), 766-771. doi: 10.1016/j.jpainsymman.2017.07.031

based performance measures in hospice and palliative care is illustrated by the initial inclusion and subsequent discontinuation of the National Quality Forum (NQF)-endorsed Comfortable Dying measure (#0209) in the Hospice Quality Reporting Program (HQRP). In the final rule for FY 2014, CMS offered the following explanation for dropping the measure:

“First, the measure does not easily correspond with the clinical processes for pain management, resulting in variance in what hospices collect, aggregate, and report. This concern could potentially be addressed by extensive and ongoing provider training or standardizing data collection. However, even with extensive training and the use of a standardized item set during the pilot test, the data showed continued variance in implementation of the measure. Second, there is a high rate of patient exclusion due to patient ineligibility for the measure and patients’ denying pain at the initial assessment. This high rate of patient exclusion from the measure results in a small denominator and creates validity concerns. These concerns cannot be addressed by training or standardizing data collection.”<sup>35</sup>

We are committed to the exploration of PROs and associated performance measures that go beyond the experience of care for the seriously ill population receiving community-based palliative care. Some PRO instruments show promise, but are in too early a stage of testing and adoption in the U.S. to include in our proposed APM; the Integrated Palliative Outcome Scale (IPOS), developed and validated in the United Kingdom, is a good example<sup>36</sup>.

AAHPM is committed to bridging these gaps and driving quality improvement that matters in Hospice and Palliative Medicine (HPM). Top national experts on quality measure development, implementation and improvement serve on the Academy’s APM Task Force and Quality Committees. Additionally, to empower Hospice and Palliative Medicine professionals to deliver the best quality care possible to people living with serious illness, AAHPM is currently working with hospice and palliative care leaders and organizations, foundations, and other stakeholders on a broad range of projects, including:

1. **Measure development:** AAHPM, in collaboration with the American Medical Group Association, OptumLabs, and the National Quality Forum’s Measure Incubator project, has been awarded grant funding from AARP to develop and test new pain treatment and other outcomes measures in a seriously ill population using a commercial clinical and claims database. A highlight of this work is the development and testing of a quality measure denominator that captures the seriously ill population appropriate for palliative care across a broad range of diagnoses and care settings.
2. **Registries collaborative project:** Supported by a grant from the Gordon and Betty Moore Foundation, AAHPM has partnered with organizations that currently offer HPM specialty registries – including the Center to Advance Palliative Care, National Palliative Care Research Center, Global Palliative Care Quality Alliance, and Palliative Care Quality Network – to explore models for unifying the registries and expanding the Academy’s role as the supporting national medical specialty society.

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<sup>35</sup> <https://www.gpo.gov/fdsys/pkg/FR-2013-08-07/pdf/2013-18838.pdf>, page 48256. Accessed on November 4, 2017

<sup>36</sup> <https://pos-pal.org/maix/pos-and-ipos-summary.php>. Accessed on November 4, 2017

3. **AAHPM/HPNA Measuring What Matters workgroups:** The Technical Specifications for electronic Clinical Quality Measures (eQMs) Workgroup aims to partner with EHR vendors and other stakeholders to develop specifications for eQMs that matter for patients with serious illness and their families. The Quality Improvement (QI) Education and Strategies Workgroup is developing quality improvement and educational resources to drive better patient care while helping clinicians to meet requirements for value-based reimbursement, Continuing Medical Education (CME) and Maintenance of Certification (MOC) whenever possible.
4. **National Coalition for Hospice and Palliative Care (NCHPC) Quality Work Group:** AAHPM is working with other coalition member stakeholder organizations and RTI International on a proposal to submit in response to a CMS Request For Proposals (RFP) titled *Medicare Access and CHIP Reauthorization Act (MACRA) Funding Opportunity: Measure Development for the Quality Payment Program*. This program would release cooperative grant funds (up to \$6 million over a 3-year period) to develop measures in critical gap areas, such as palliative care. It is expected to open to proposals early in 2018. The NCHPC Quality Workgroup plans to propose development of two measures, a patient-reported outcome measure of symptom management and an assessment of caregiver needs and support.
5. **National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care:** AAHPM is a core member of the NCHPC, the host organization for the NCP guidelines. With a grant from the Gordon and Betty Moore Foundation, NCHPC is updating its NCP guidelines for a 4th edition targeted for release in July 2018. This update will address palliative care in all settings, including the growing trend of community-based palliative care. AAHPM participated in the July 2017 NCP Summit in Chicago and has representatives on both the steering committee and writing workgroup.

As much as possible, we have based our proposed quality accountability structure on existing measures in common use that have been endorsed by the National Quality Forum or recommended by Measuring What Matters (MWM), but we have had to modify them for use in a community-based palliative care setting. Where it makes sense, we have also given consideration to harmonizing our measures with the Hospice Item Set and Hospice CAHPS survey that are currently used in the Hospice Quality Reporting Program. We have avoided measures that are topped out or show little variability in palliative care settings. In particular, we considered the variability of MWM quality indicators reported to the Global Palliative Care Quality Alliance using the QDACT tool<sup>37</sup>. We have focused on determinants of value, including the experience of care for patients and caregivers, processes and outcomes associated with quality palliative care, and utilization of services that are

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<sup>37</sup> Kamal, A., Bull, J., C., Hanson, L., Friedman, F., D., & AAHPM Research Committee Writing Group. (2016). Adherence to Measuring What Matters Measures Using Point-of-Care Data Collection Across Diverse Clinical Settings. *Journal of Pain and Symptom Management*, 51(3), 497-503. doi:doi: 10.1016/j.jpainsymman.2015.12.313

desirable or undesirable to most Medicare beneficiaries at the end of life<sup>38,39</sup>. We have included some new or modified measures that are in various stages of active development, including a post-admission experience of care survey for people receiving community-based palliative care (or the primary caregiver, usually a close family member, for those incapable of completing the survey), a post-death survey for the primary caregivers of those who die without receiving hospice care and a process measure of documentation of a structured assessment of caregiver needs and distress.

Each proposed quality measure's specifications, modifications and current stage of development are described below.

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**PACSSI Measure #1 Patient or Caregiver Post-Admission Experience of Care Survey**

**Measure Type** Patient (or caregiver) reported outcome performance measure (experience of care)

**New, Modified or Established?** Modified

**Based on What Original Measure?** Hospice CAHPS Survey

**Is Original Measure Endorsed by NQF?** Yes #2651

**Is Original Measure Recommended by WMW?** Yes, MWM #10

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes

**Is PACSSI Measure Currently Used by Palliative Care Teams?** No

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** Not applicable

**Original Measure Steward** CMS

**Original Measure Specifications** Specifications can be found by searching for measure #2651 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

**How Is Original Measure Modified for PACSSI?** Timing is 30 days post-admission.

Informant is patient (or, if incapacitated, primary caregiver). Target population is patients enrolled in community-based palliative care (CBPC). Domains and items are similar to CAHPS, but items focused on end of life are not included and items focused on the quality of communication with the palliative care team are expanded. Communication items include:

- Whether the information was presented in a way the person could understand;
- Whether the health care professionals communicated in a sensitive manner;
- Whether the seriously ill person and family were allowed to ask questions; and
- Whether they were able to make a decision without feeling pressured by the health care team to make a decision that they did not want.

Patients who have died or were enrolled in CBPC for less than 7 days are excluded. For incapacitated patients, a separate survey is administered to the primary caregiver, including similar items for which a surrogate's perception is valid and additional items about the

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<sup>38</sup> Barnato, A., Herndon, M., Anthony, D., Gallagher, P., Skinner, J., Bynum, J., & Fisher, E. (2007). Are regional variations in end-of-life care intensity explained by patient preferences?: A Study of the US Medicare Population. *Med Care*, 45, 5th ser., 386-393

<sup>39</sup> Barnato, A. E., Anthony, D. L., Skinner, J., Gallagher, P. M., & Fisher, E. S. (2009). Racial and Ethnic Differences in Preferences for End-of-Life Treatment. *Journal of General Internal Medicine*, 24(6), 695-701. doi:10.1007/s11606-009-0952-6

caregiving experience (e.g. “How often did you receive the education and training you needed to care for the seriously ill person?”). As much as possible, this survey will be designed to harmonize with the Hospice CAHPS survey, and it will use the same top box scoring methodology.

**Source of Measure Data** Standardized survey instrument, administered by third party.

**Current State of Development of PACSSI Measure** Joan M. Teno, MD MS, co-chair of the AAHPM Quality Payment Workgroup, has submitted a grant proposal to develop this survey. She expects a funding decision before the end of this year<sup>40</sup>.

**Who Is Responsible for Modification or Development?** Joan M. Teno, MD MS, Professor of Gerontology and Geriatric Medicine, University of Washington, and AAHPM.

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**PACSSI Measure #2** Post-Death Experience of Care Survey

**Measure Type** Patient (family surrogate) reported outcome performance measure (experience of care)

**New, Modified or Established?** Modified

**Based on What Original Measure?** Hospice CAHPS Survey

**Is Original Measure Endorsed by NQF?** Yes #2651

**Is Original Measure Recommended by WMW?** Yes, MWM #10

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes

**Is PACSSI Measure Currently Used by Palliative Care Teams?** No

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** Not applicable

**Original Measure Steward** CMS

**Original Measure Specifications** Specifications can be found by searching for measure #2651 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

**How Is Original Measure Modified for PACSSI?** Target population is the primary bereaved family member, for patients who died while receiving community-based palliative care (CBPC). This survey will be designed to harmonize with the Hospice CAHPS survey, and it will use the same top box scoring methodology.

**Source of Measure Data** Standardized survey instrument, administered by third party.

**Current State of Development of PACSSI Measure** The Rand Corporation expects to begin work soon on development of a survey of this type<sup>41</sup>.

**Who Is Responsible for Modification or Development?** The Rand Corporation

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<sup>40</sup> Personal communication between Dr. Joe Rotella (AAHPM) and Dr. Joan Teno, on October 23, 2017

<sup>41</sup> Personal communication between Dr. Joe Rotella (AAHPM) and Dr. Joan Teno, on October 23, 2017

**PACSSI Measure #3** Hospice CAHPS Post-Death Experience of Care Survey  
**Measure Type** Patient (family surrogate) reported outcome performance measure (experience of care)  
**New, Modified or Established?** Established  
**Based on What Original Measure?** Hospice CAHPS  
**Is Original Measure Endorsed by NQF?** Yes #2651  
**Is Original Measure Recommended by WMW?** Yes, MWM #10  
**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes  
**Is PACSSI Measure Currently Used by Palliative Care Teams?** No  
**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No  
**Original Measure Steward** CMS  
**Original Measure Specifications** Specifications can be found by searching for measure #2651 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

**How Is Original Measure Modified for PACSSI?** The measure is used as currently specified for patients who die receiving hospice care. The modification is that, for all patients who die within seven days of discharge from PACSSI to hospice care, the Hospice CAHPS results are attributed to the PACSSI team as well as the hospice and count the same as the PACSSI Measure #2: Post-Death Experience of Care Survey.  
**Source of Measure Data** Standardized survey instrument, administered by third party.  
**Current State of Development of PACSSI Measure** Established  
**Who Is Responsible for Modification or Development?** CMS

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**PACSSI Measure #4** Completion of a Comprehensive Assessment Soon After Admission  
**Measure Type** Process  
**New, Modified or Established?** Modified  
**Based on What Original Measure?** PEACE Measure Set: Percent of Patients Who Have Comprehensive Assessment (Documentation of Prognosis, Functional Status, Screening for Physical and Psychological Symptoms and Assessment of Social and Spiritual Needs) Completed Within 5 Days of Admission  
**Is Original Measure Endorsed by NQF?** Yes #3235 (composite measure)  
**Is Original Measure Recommended by WMW?** Yes, MWM #1  
**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes  
**Is PACSSI Measure Currently Used by Palliative Care Teams?** Yes  
**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No  
**Original Measure Steward** The University of North Carolina – Chapel Hill  
**Original Measure Specifications** Specifications can be found by searching for measure #3235 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

Specifications for the original PEACE measure set are available on the University of North Carolina PEACE measures web site: <https://www.med.unc.edu/pcare/files/specifications-for-recommended-quality-measures>

**How Is Original Measure Modified for PACSSI?** Target population is patients admitted to community-based palliative care (CBPC). The time interval is increased to completion of all items within 15 days of admission to CBPC.

**Source of Measure Data** Medical record extraction, electronic or manual

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** Global Palliative Care Quality Alliance (GPCQA) and AAHPM

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**PACSSI Measure #5** Screening for Physical Symptoms Soon After Admission

**Measure Type** Process

**New, Modified or Established?** Modified

**Based on What Original Measure?** PEACE Measure Set: Percent of Patients Screened for Pain, Dyspnea, Nausea and Constipation

**Is Original Measure Endorsed by NQF?** No for Composite measure; Yes for individual items, Pain Screening #1634 and Dyspnea Screening #1639

**Is Original Measure Recommended by WMW?** Yes, MWM #2

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes

**Is PACSSI Measure Currently Used by Palliative Care Teams?** Yes

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No

**Original Measure Steward** The University of North Carolina at Chapel Hill

**Original Measure Specifications** Specifications can be found by searching for measures #1634 and # 1639 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

Specifications for the original PEACE measure set are available on the University of North Carolina PEACE measures web site: <https://www.med.unc.edu/pcare/files/specifications-for-recommended-quality-measures>

**How Is Original Measure Modified for PACSSI?** Target population is patients admitted to community-based palliative care (CBPC). The time interval is increased to completion within 15 days of admission to CBPC.

**Source of Measure Data** Medical record extraction, electronic or manual

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** GPCQA and AAHPM

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**PACSSI Measure #6** Documentation of a Discussion Regarding Emotional Needs or Screening for Anxiety and Depression Soon After Admission

**Measure Type** Process

**New, Modified or Established?** Modified

**Based on What Original Measure?** PEACE Measure Set: Percent of Patients Who Have Screening for Psychological Symptoms Within 5 Days of Admission

**Is Original Measure Endorsed by NQF?** No

**Is Original Measure Recommended by WMW?** Yes, MWM #5

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** No

**Is PACSSI Measure Currently Used by Palliative Care Teams?** Yes

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No

**Original Measure Steward** The University of North Carolina – Chapel Hill

**Original Measure Specifications** Specifications for the original PEACE measure set are available on the University of North Carolina PEACE measures web site:

<https://www.med.unc.edu/pcare/files/specifications-for-recommended-quality-measures>

**How Is Original Measure Modified for PACSSI?** Target population is patients admitted to community-based palliative care (CBPC). The time interval is increased to completion within 15 days of admission to CBPC. Met by documenting either the use of a screening tool for anxiety and depression or a discussion of emotional needs.

**Source of Measure Data** Medical record extraction, electronic or manual

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** GPCQA and AAHPM

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**PACSSI Measure #7** Documentation of a Discussion Regarding Spiritual Concerns or Screening with “Do You Have Any Unmet Spiritual Needs?”

**Measure Type** Process

**New, Modified or Established?** Modified

**Based on What Original Measure?** PEACE Measure Set: Percent of Patients Who Have Documentation of a Discussion of Spiritual Concerns Within 5 Days of Admission

**Is Original Measure Endorsed by NQF?** Yes, #1647

**Is Original Measure Recommended by WMW?** Yes, MWM #6

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes

**Is PACSSI Measure Currently Used by Palliative Care Teams?** Yes

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No

**Original Measure Steward** The University of North Carolina – Chapel Hill

**Original Measure Specifications** Specifications can be found by searching for measure #1647 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

Specifications for the original PEACE measure set are available on the University of North Carolina PEACE measures web site: <https://www.med.unc.edu/pcare/files/specifications-for-recommended-quality-measures>

**How Is Original Measure Modified for PACSSI?** Target population is patients admitted to community-based palliative care (CBPC). The time interval is increased to completion within 15 days of admission to CBPC. Met by documenting either a discussion of emotional needs or screening with the question “Do you have any unmet spiritual needs?”

**Source of Measure Data** Medical record extraction, electronic or manual

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** GPCQA and AAHPM

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**PACSSI Measure #8** Documentation of a Discussion about Advance Care Planning, Including Preferences for Surrogate Decision-maker(s) and Life-sustaining Treatments

**Measure Type** Process

**New, Modified or Established?** Modified

**Based on What Original Measure?** PEACE Measure Set: Percent of patients with chart documentation of preferences for life sustaining treatments, and Percent of patients with contact information for surrogate decision maker in the chart or documentation that there is no surrogate

**Is Original Measure Endorsed by NQF?** Partially, #1641 (preferences for life-sustaining treatments)

**Is Original Measure Recommended by WMW?** Yes, MWM #8 and #9

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** Yes

**Is PACSSI Measure Currently Used by Palliative Care Teams?** Yes

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No

**Original Measure Steward** The University of North Carolina – Chapel Hill

**Original Measure Specifications** Specifications can be found by searching for measure #1641 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

Specifications for the original PEACE measure set are available on the University of North Carolina PEACE measures web site: <https://www.med.unc.edu/pcare/files/specifications-for-recommended-quality-measures>

**How Is Original Measure Modified for PACSSI?** Target population is patients admitted to community-based palliative care (CBPC). The time interval is increased to completion within 15 days of admission to CBPC. Met by documenting both surrogate decision maker (or absence of one) and a discussion of preferences for life-sustaining treatments.

**Source of Measure Data** Medical record extraction, electronic or manual

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** GPCQA and AAHPM

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**PACSSI Measure #9** Completion of a Structured Assessment of Caregiver Needs and Distress  
**Measure Type** Process  
**New, Modified or Established?** New  
**Based on What Original Measure?** Not Applicable  
**Is Original Measure Endorsed by NQF?** Not Applicable  
**Is Original Measure Recommended by WMW?** Not Applicable  
**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** No  
**Is PACSSI Measure Currently Used by Palliative Care Teams?** No  
**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** Not Applicable  
**Original Measure Steward** Not Applicable  
**Original Measure Specifications** Not developed yet  
**How Is Original Measure Modified for PACSSI?** Not Applicable  
**Source of Measure Data** Medical record extraction, electronic or manual  
**Current State of Development of PACSSI Measure** Planning stage.  
**Who Is Responsible for Modification or Development?** National Coalition for Hospice and Palliative Care is working with RTI International on a proposal to CMS to develop this measure.

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**PACSSI Measure #10** Percentage of Patients Who Died Receiving Hospice Care  
**Measure Type** Outcome (utilization)  
**New, Modified or Established?** Modified  
**Based on What Original Measure?** ASCO QOPI Measure: Proportion of Patients Who Died From Cancer Not Admitted to Hospice  
**Is Original Measure Endorsed by NQF?** Yes, #0215  
**Is Original Measure Recommended by WMW?** No  
**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** No  
**Is PACSSI Measure Currently Used by Palliative Care Teams?** Yes  
**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** No  
**Original Measure Steward** American Society of Clinical Oncology  
**Original Measure Specifications** Specifications can be found by searching for measure #0215 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>  
**How Is Original Measure Modified for PACSSI?** Target population is all patients who were admitted to community-based palliative care (CBPC) and subsequently died. The PACSSI measure is posed as the inverse of the ASCO measure (desirable outcome is a higher rather than lower score to be consistent with all other PACSSI measures).  
**Source of Measure Data** Claims  
**Current State of Development of PACSSI Measure** Ready to implement.  
**Who Is Responsible for Modification or Development?** AAHPM

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**PACSSI Measure #11** Percentage of Patients Who Died and Were Admitted to Hospice for More than 7 days

**Measure Type** Outcome (utilization)

**New, Modified or Established?** Modified

**Based on What Original Measure?** ASCO QOPI Measure: Proportion of Patients Who Died From Cancer Admitted to Hospice For Less Than Three Days

**Is Original Measure Endorsed by NQF?** Yes, #0216

**Is Original Measure Recommended by WMW?** No

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** No

**Is PACSSI Measure Currently Used by Palliative Care Teams?** No

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** Not Applicable

**Original Measure Steward** American Society of Clinical Oncology

**Original Measure Specifications** Specifications can be found by searching for measure #0216 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

**How Is Original Measure Modified for PACSSI?** Target population is all patients who were admitted to community-based palliative care (CBPC) for more than 15 days and subsequently died. The minimum duration of hospice care is increased from three to seven days.

**Source of Measure Data** Claims

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** AAHPM

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**PACSSI Measure #12** Percentage of Patients Who Died With No Days In ICU During the Last 30 Days of Life

**Measure Type** Outcome (utilization)

**New, Modified or Established?** Modified

**Based on What Original Measure?** ASCO QOPI Measure: Proportion of Patients Who Died From Cancer Admitted to ICU in Last 30 Days of Life

**Is Original Measure Endorsed by NQF?** Yes, #0213

**Is Original Measure Recommended by WMW?** No

**Does PACSSI Measure Harmonize with Hospice Item Set or Hospice CAHPS Survey?** No

**Is PACSSI Measure Currently Used by Palliative Care Teams?** No

**Does PACSSI Measure Show Signs of Low Variability or Topping Out?** Not Applicable

**Original Measure Steward** American Society of Clinical Oncology

**Original Measure Specifications** Specifications can be found by searching for measure #0213 on the NQF website: <http://www.qualityforum.org/QPS/QPSTool.aspx>

**How Is Original Measure Modified for PACSSI?** Target population is all patients who were admitted to community-based palliative care (CBPC) for more than 30 days and subsequently died. The PACSSI measure is posed as the inverse of the ASCO measure (desirable outcome is a higher rather than lower score to be consistent with all other PACSSI measures).

**Source of Measure Data** Claims

**Current State of Development of PACSSI Measure** Ready to implement.

**Who Is Responsible for Modification or Development?** AAHPM

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**10. Although the proposal states that patient reported outcome measures will be used in the model (Category 1 measures), the PRT observed only one of the 21 proposed measures listed on pages 11-13 as measuring reduction of patient pain and suffering (the first listed benefit of palliative care identified on page 1 of the proposal). We understand that this measure (i.e., “adequacy of treatment for pain and symptoms”) has not yet been developed and would be part of a to-be-developed Admission Survey. Do we understand this correctly? Will this Item set comprise one patient-reported outcome measure or more than one? If more than one, please identify the aspects of patient pain and suffering to be addressed in the item set.**

All of the new surveys to be developed for PACSSI’s quality reporting program will be patterned closely after the Hospice CAHPS survey and will include similar symptom control questions.

For the patient post-admission survey, the following items will be included:

1. While you were receiving palliative care, did you have any pain?
  - <sup>1</sup>Yes
  - <sup>2</sup>No
  
2. [IF YES] Did you get as much help with pain as you needed?
  - <sup>1</sup>Yes, definitely
  - <sup>2</sup>Yes, somewhat
  - <sup>3</sup>No
  
3. While you were receiving palliative care, did you ever have trouble breathing?
  - <sup>1</sup>Yes
  - <sup>2</sup>No
  
4. [IF YES] How often did you get the help you needed for trouble breathing?
  - <sup>1</sup>Never
  - <sup>2</sup>Sometimes
  - <sup>3</sup>Usually
  - <sup>4</sup>Always

For the caregiver post-admission and post-death surveys, the following items will be included:

1. While your family member was receiving palliative care, did he or she have any pain?
  - <sup>1</sup>Yes
  - <sup>2</sup>No
  
2. [IF YES] Did your family member get as much help with pain as he or she needed?
  - <sup>1</sup>Yes, definitely
  - <sup>2</sup>Yes, somewhat
  - <sup>3</sup>No

3. While your family member was receiving palliative care, did he or she ever have trouble breathing?
  - <sup>1</sup>Yes
  - <sup>2</sup>No
  
4. [IF YES] How often did your family member get the help he or she needed for trouble breathing?
  - <sup>1</sup>Never
  - <sup>2</sup>Sometimes
  - <sup>3</sup>Usually
  - <sup>4</sup>Always

The other items in the experience of care survey also represent significant patient-reported outcomes. In palliative care, the separation of the patient's experience of care from other measurable outcomes is to some degree artificial. The patient's perceptions that the health care team is caring and compassionate, listens and explains things well, and always treats him or her with dignity and respect are key drivers in restoring the patient's hope and sense of control, relieving suffering and maximizing quality of life.

**11. The proposal (on page 1) identifies the benefits of palliative care as:**

- **Reducing pain and suffering patients experience due to their illnesses;**
- **Reducing stresses and physical burdens on caregivers that can create or worsen their health problems;**
- **Increasing caregiver satisfaction;**
- **Reducing the number of times patients visit emergency departments due to burdensome symptoms or exacerbations of their health conditions; and**
- **Reducing unnecessary office visits to specialists for routine follow-up care.**

**Please identify which measures address these. How will the model distinguish between appropriate and inappropriate use of hospital, ED, and ICU care?**

The PACSSI model will generate a host of data that can be used in different ways. A limited number of quality and cost measures provide accountability at the level of the participating palliative care team, resulting in adjustments to its incentive payments or share of losses or savings. However, we expect that other effects of the model on the outcomes listed above will nonetheless be tracked, including through the model evaluation and through initiatives undertaken by the learning collaborative (described on page 9 of the proposal), and that such initiatives may drill down on quality or cost drivers and consider data on a much more granular level. For example, PACSSI employs a total cost of care measure to benchmark spending and adjust payments to palliative care teams, but a learning collaborative might look at many different categories of cost, such as facility charges, physician fees, DME, treatments and tests, in order to identify opportunities to manage them better.

Some of the benefits of palliative care on the bulleted list are specifically reflected in the quality and cost measures proposed for accountability and linked to payment, and we provide greater detail below. Others are not specifically addressed but roll up into more general accountability measures. All are appropriate targets for study by a payment model evaluator or learning collaborative.

**Reducing pain and suffering patients experience due to their illnesses**

PACSSI Measures #1, #2 and #3 are patient or caregiver surveys administered post-admission or post-death. All include items about the adequacy of treatment for pain and trouble with breathing. (See specific survey questions in answer to question 10.)

PACSSI Measures #4, #5, #6, and #7 are process measures that address the components of a comprehensive assessment on admission to identify physical, emotional and spiritual needs, the foundation for developing a palliative care plan to prevent and relieve suffering in body, mind, heart and spirit.

**Reducing stresses and physical burdens on caregivers that can create or worsen their health problems**

PACSSI Measure #1 includes a post-admission survey of the caregiver's experience of care for patients who are incapable of completing the survey themselves. The caregiver survey includes additional items about the caregiving experience (e.g. "How often did you receive

the education and training you needed to care for the seriously ill person?”). PACSSI Measures #2 and #3 are post death surveys that also include items on the caregiving experience.

PACSSI Measure #9 is a process measure that addresses the completion of a structured assessment of caregiver needs and distress as an additional component of the admission comprehensive assessment.

### **Increasing caregiver satisfaction**

As described above, PACSSI Measures #1, #2 and #3 are surveys that can shed light on the caregiver’s experience of care at a greater depth than just overall satisfaction.

PACSSI Measure #9, a structured assessment of caregiver needs and distress, forms the basis for including interventions in the palliative care plan to prevent and relieve caregiver suffering.

### **Reducing the number of times patients visit emergency departments due to burdensome symptoms or exacerbations of their health conditions**

PACSSI Measures #4, #5, #6, #7 and #9 are process measures for the components of a comprehensive assessment on admission that informs the palliative care plan to prevent and relieve suffering for the patient and caregiver. Identifying these needs allows the palliative care team to intervene and prevent the crises of uncontrolled symptoms, disease exacerbation or caregiver exhaustion that frequently lead to emergency department visits.

In addition, PACSSI Measure #8 addresses patient preferences for life sustaining treatments and designation of a surrogate decision maker. This process of advance care planning can prevent unwanted emergency department visits for patients who prefer to forgo life-sustaining treatments and spend as much time as possible at home.

Emergency department visits will contribute to the PACSSI total cost of care measure and will certainly be studied by the learning collaborative and model evaluators.

### **Reducing unnecessary office visits to specialists for routine follow-up care**

Reductions in unnecessary office visits are an expected outcome of completing a comprehensive assessment, determining the patient’s goals of care, developing a palliative care plan and coordinating care with all other healthcare providers. We expect that reductions in unnecessary office visits will appear in both evaluation results and in contributions to the PACSSI total cost of care measure.

### **How will the model distinguish between appropriate and inappropriate use of hospital, ED, and ICU care?**

The approach AAHPM has taken in designing the accountability for quality and cost in the PACSSI model does not rely on retrospectively determining the appropriateness of utilization of hospital, ED, ICU or hospice care. As detailed in the proposal, there is convincing evidence that community-based palliative care decreases use of hospital, ED and

ICU care and increases use of hospice care while improving quality of life and delivering a better experience of care. Palliative care teams engage with individual patients and families to discern what is appropriate for them in their specific circumstances, based on their needs, goals and preferences, and strive to make shared medical decisions. In the setting of serious illness, how patients and families perceive the benefits and burdens of treatments and care interventions is influenced by many factors, not just medical problems, but also social determinants, family dynamics, emotional and spiritual concerns, attitudes toward death and dying, shifting goals of care and more. The palliative care team takes an active role in advance care planning, shared decision-making and care coordination, but other primary or specialty care teams may also be engaged in the patient's care and influence the decisions they make. Research on the preferences of Medicare beneficiaries for care near the end of life indicates that a large majority would prefer to spend their last days in comfort at home and forgo life supports that would only extend life for a brief time<sup>42, 43</sup>. There are times, though, when a hospital, ED or ICU stay is appropriate or a hospice referral is inappropriate, even near the end of life. AAHPM recognizes the challenges this situation poses for benchmarking utilization measures, but it is our opinion that attempting to determine appropriateness of utilization on a retrospective review of claims would pose undue burden with dubious benefit.

PACSSI Measures # 10, 11 and 12, which address hospice and ICU days near the end of life, are based on measures originally developed by the American Society of Clinical Oncology (ASCO) and endorsed by NQF that do not include risk adjustments or exclusions and do not distinguish appropriate from inappropriate use of these services. Our modification of the measures for use in the broader population of patients receiving community-based palliative care keeps that original methodology intact. See the answer to question 13 below for more detail on our approach to benchmarking these utilization measures.

We have not proposed any accountability measures that specifically address ED visits or hospital stays. Instead, the quality and cost implications of these interventions are rolled up into the more global measures of the experience of care and total cost of care.

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<sup>42</sup> Barnato, A., Herndon, M., Anthony, D., Gallagher, P., Skinner, J., Bynum, J., & Fisher, E. (2007). Are regional variations in end-of-life care intensity explained by patient preferences?: A Study of the US Medicare Population. *Med Care*, 45, 5th ser., 386-393

<sup>43</sup> Barnato, A. E., Anthony, D. L., Skinner, J., Gallagher, P. M., & Fisher, E. S. (2009). Racial and Ethnic Differences in Preferences for End-of-Life Treatment. *Journal of General Internal Medicine*, 24(6), 695-701. doi:10.1007/s11606-009-0952-6

**12. A number of quality measures are proposed to be obtained from a survey of the patient and family. How will difference of opinions of the patient and the family or caregiver be detected? Who will administer the survey?**

In light of the challenges in implementing performance measures based on patient-reported outcomes for people living with serious illness (as described in the answer to question 9 above), the outcomes that have been most useful to date are those based on retrospective surveys of the experience of care administered after the patient's death to an appropriate proxy (primary caregiver or bereaved family member). The retrospective nature of such surveys and reliance on proxy respondents poses both challenges and opportunities<sup>44</sup>. Family members and other caregivers are important actors in the patient's experience and at risk of suffering themselves. The palliative care team assesses their needs and distress and includes interventions to support them in the palliative care plan. In fact, the World Health Organization's definition of palliative care recognizes the patient *and family* as the unit of care<sup>45</sup>. In retrospective surveys, such as the Hospice CAHPS (PACSSI Measure #3) and the post-death survey for patients not receiving hospice care (PACSSI Measure #2), in addition to items about their perception of the patient's experience, proxies are also asked about their own experience as partners in the patient's care.

The PACSSI quality accountability framework adds a new prospective post-admission survey (PACSSI Measure #1) for which the primary intended respondent is the patient; a separate survey would only be administered to the caregiver proxy when the patient is incapable of completing the survey. There are several reasons to use a proxy for the post-admission survey when necessary. First, if we limited the survey to patients capable of responding for themselves, we would exclude significant segments of the palliative care population, such as those with advanced dementia and other neurologic degenerative conditions. In addition, as a person living with serious illness becomes more frail and closer to dying, family members and other caregivers take on a larger role in coordinating and providing care. They become expert observers, and patients rely on them to help them make medical decisions. When administered to a proxy, the prospective post-admission survey will include a limited set of items for which the respondent will act as proxy for the patient's experience of care and additional questions about aspects of care delivery that the proxy participated in or observed directly. Thus, all surveys in the PACSSI quality program that are administered to proxies will include a subset of items that addresses the proxy's own experience.

The surveys address patient and proxy perceptions about the care delivered. Differences of opinion between patients and proxies are certainly possible, but it is beyond the scope of these surveys to assess that. We mitigate the effect of differences of opinion by having patients and proxies primarily report *their own experience*.

As with the Hospice CAHPS, we expect that all surveys would be administered in various modalities by an independent third party who meets CMS requirements.

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<sup>44</sup> Teno, J. M. (2005). Measuring End-of-Life Care Outcomes Retrospectively. *Journal of Palliative Medicine*, 8 (Supplement 1). doi:10.1089/jpm.2005.8.s-42

<sup>45</sup> <http://www.who.int/cancer/palliative/definition/en/> Accessed on November 4, 2017

### 13. With respect to the three proposed utilization measures:

- Percentage of patients who died who received hospice care;
- Percentage of patients who died and were enrolled in hospice more than 7 days before death; and
- Percentage of patients who died and did not have any days in an ICU during the 30 days before death.

**What is the target rate for these measures and what is the evidence that the target rate represents best outcome for the patients? As above, how will the model distinguish between appropriate and inappropriate use of ICU care?**

As discussed in the answer to question #11 above, the three utilization measures (PACSSI Measures #10, #11 and #12) are not adjusted based on any determination of appropriate or inappropriate indications. The measures will be reported and studied during the first two years of the model demonstration before benchmarks are set and pay-for-performance starts in year three. Infrequently, ICU care is appropriate in the last 30 days of life. Likewise, for a variety of reasons, not all patients will choose to enroll in hospice care. The target rates should therefore not be 100%. To set target rates for these utilization measures, AAHPM would expect to work closely with CMS and other partners and consider historical utilization, the identified preferences for most Medicare beneficiaries, evidence for similar populations, analysis of trends and outliers during the first two years of the PACSSI model demonstration, and correlations with results of the experience of care surveys.

Trends in hospice utilization are reported in “Facts and Figures: Hospice Care in America,” 2016 Edition, recently published by the National Hospice and Palliative Care Organization<sup>46</sup>. Of all Medicare decedents in 2015, 46% received one day or more of hospice care and were enrolled in hospice at the time of death. 28.2% were enrolled in hospice care for seven days or less. As supported by the previously referenced palliative care literature, AAHPM expects the PACSSI model to drive more timely access to hospice care, so target rates for PACSSI Measures #10 and #11 would be set considerably higher than these historical precedents.

AAHPM expects the PACSSI model to decrease ICU use near end of life. One home-based palliative care program reported significant reductions in the percentage of patients who had ICU stays in the last 30 days of life across four disease categories (cancer, COPD, CHF and dementia) with results ranging from 8.7 to 13.8% (which would correlate in our inverted measure to rates of 86-91%)<sup>47</sup>. Since the PACSSI measure is based on an ASCO measure used in the Merit-based Incentive Payment System (MIPS) and the ASCO Quality Oncology Practice Initiative (QOPI), we would expect to have a wealth of experience to bring to bear on the setting of a target rate for this measure.

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<sup>46</sup> NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, September 2017. [https://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2016\\_Facts\\_Figures.pdf](https://www.nhpco.org/sites/default/files/public/Statistics_Research/2016_Facts_Figures.pdf). Accessed on November 4, 2017

<sup>47</sup> Cassel, J. B., Kerr, K. M., Mcclish, D. K., Skoro, N., Johnson, S., Wanke, C., & Hoefler, D. (2016). Effect of a Home-Based Palliative Care Program on Healthcare Use and Costs. *Journal of the American Geriatrics Society*, 64(11), 2288-2295. doi:10.1111/jgs.14354

#### **14. How does will the model guard against 1) unintended consequences and 2) stinting on hospital care and on other services that lead to adverse outcomes?**

There are many safeguards within the PACSSI model to mitigate the risks of unintended consequences and stinting on care. First, patients are only enrolled in PACSSI after a process of informed consent (see answer to question #3 above), and they are free to continue seeing their primary care physician and/or other specialists (for anything besides chronic care management services) and to disenroll at any time they want. The new experience of care surveys (PACSSI Measures #1 and #2) will include items on the patient's or proxy's perceptions of the adequacy of treatment for pain and trouble with breathing, quality of communication with the palliative care team, timeliness of response to urgent needs, and access to needed care. The learning collaborative will provide a platform to identify and promulgate best practices in patient care and to study trends and outliers in outcomes, key care processes, and health care utilization and costs. Although the palliative care teams have some accountability for the total cost of care, they are not positioned as intermediary payers. They are responsible for coordinating care, but it would be inappropriate for them to engage in pre-authorization or other overt cost containment strategies. In addition, the possibility that some PCTs might avoid enrolling patients who could drive higher healthcare costs ("cherry picking") is mitigated by requiring PCTs to accept all patients who are referred to them who meet the eligibility requirements. As described on page seven of the proposal,

"In order to receive PACSSI payments, a PCT would be required to accept any patient living in the service area who met the eligibility criteria, unless the team had reached a pre-defined capacity limit. If the PCT were unable to serve a patient due to the capacity limit, it would be required to establish a waiting list. If changes in the existing patients under the PCT's care enabled the PCT to accept additional patients, it would be required to accept patients from the waiting list before accepting new patients."

Furthermore, the model evaluator can use claims data to identify PCTs who are outliers based on case mix by diagnosis, length of service or patterns of healthcare utilization and cost.

The PACSSI process measures (Measures #4, #5, #6, #7, #8 and #9) will ensure that palliative care teams complete a comprehensive assessment, including caregiver needs and distress, and document the patient's preferences for life-sustaining treatments and health care surrogate, all of which forms the foundation for a palliative care plan targeted to each patient's and family's individual needs, goals and preferences. Along with a wealth of quality and claims data, we would expect the model evaluator to track and trend any patient complaints received. Palliative care teams that persistently do not meet certain minimum quality expectations or who have an unusual number of verified complaints would be terminated from participation in the payment model.

**15. Page 13 of the proposal states that, “When fully phased in, PCTs’ accountability for quality performance would be based on a composite score that equally weights performance across each of the three quality categories.” (patient reported experience, care processes, and utilization rates). How did you determine that these should be equally weighted?**

The palliative care quality subject matter experts that AAHPM convened to design the PACSSI quality accountability framework proposed a balanced approach that uses both the best performance measures and data sources available right now and those they expect to be ready to use within the next two years. The three broad categories of patient-reported experience, key care processes and utilization of particularly desirable or undesirable services at the end of life complement each other and provide the most complete picture possible under those constraints. There is currently no evidence to support giving any of the three components more initial weight than the others. During the first two years of the model demonstration, only the process measures based on Measuring What Matters will be ready to implement in a pay-for-performance manner. By year three, the surveys and utilization measures will be ready to implement, but it will be important to continue building on the growing experience with the process measures. We therefore have recommended an initial weighting in year three of 1-to-1-to-1 for the components of quality measurement, on a conceptual rather than empirical basis. Just as CMS has altered the relative weighting of components of the Merit-based Incentive Payment Program based on its evolving experience with implementation of MACRA, we would expect that ongoing analysis of the performance of the PACSSI model might identify a need to revise the weighting of the components after year three.

## Questions about payment methodology:

- 16. The proposed spending benchmark to be met by participating entities appears to be that the total cost of care of patients enrolled must be below “risk-adjusted spending levels.” Please describe how these spending level targets would be determined, especially given the broad eligibility criteria for enrolling in the model.**

AAHPM recognizes the inherent challenges in setting target spending levels, including with appropriate risk adjustment for high-cost, seriously ill populations, and that many of the risk adjustment methodologies currently available (e.g. the Hierarchical Conditions Categories (HCC) used for Medicare Advantage risk adjustment) are not appropriate for these populations as they are generally designed for broader populations and do not specifically account for those who may experience rapid decline and high costs near the end of life.

AAHPM envisions that target spending levels will be based on per beneficiary per month Medicare Part A and Part B costs of care for beneficiaries who meet the PACSSI eligibility criteria. Such targets could be based on historical data. Spending targets would be adjusted for factors that are known to affect patient costs, including: age; sex; primary diagnosis and comorbidities; functional status; dual eligibility; Part D enrollment; utilization of inpatient, outpatient observation, or emergency care in the 12 months prior to enrollment; and months of survival during the performance period. Adjustments that account for death during or within the three months following the performance period are particularly important given increases in spending that occur for patients near the end of life. Spending targets would also be adjusted for geographic variation and practice-specific characteristics, which are conceptually similar to adjustments adopted in other CMS models (e.g. the Oncology Care Model (OCM)). We believe that this would require a new risk-adjustment and benchmarking methodology developed specifically for the PACSSI model.

AAHPM recognizes that PACSSI eligibility criteria include several options for measuring functional status: the Palliative Performance Scale (PPS), a publicly available and broadly used assessment tool for palliative care clinicians that is considered industry standard; assessment of Activities of Daily Living (ADLs); use of DME as a proxy for functional status; or Eastern Cooperative Oncology Group (ECOG) Scale of Performance Status scores for patients with a cancer diagnosis. While DME utilization is available via claims, ADL, ECOG, and PPS data are not as readily available. However, ADL data may be extracted from quality program reporting required for those patients who receive post-acute care in home health, skilled nursing facility, long-term care hospital, and inpatient rehabilitation facility settings. Data show that approximately 55.2% of Medicare beneficiaries use these facilities in the ninety days prior to death.<sup>48</sup>

While we have outlined a broad approach to setting spending targets that are appropriately risk adjusted, we recognize that additional specification of this methodology is needed. We

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<sup>48</sup> Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *Jama*. 2013;309(5):470-477.

note that many other stakeholders have sought to address this and similar questions for the evaluation of interventions targeted towards patients with serious illness, but challenges have remained. For example, in the evaluation of the Sutter AIM model, the evaluation contractor used a propensity-matched comparison group to assess the impact of the intervention, but noted meaningful remaining discrepancies between the intervention and comparison group in terms of survival and mortality.<sup>49</sup>

While CMS has established multiple different benchmarking and risk-adjustment methodologies across various populations, CMS has not yet specifically addressed benchmarking and risk-adjustment for patients with serious illness who would benefit from community-based palliative care as delivered in PACSSI. However, CMS has access to the troves of data that would be needed to engage in analysis to develop this methodology – data to which most stakeholders are simply not privy – and has gained expertise via its past and ongoing work on model development. Given the challenges of providing high-quality, high-value care to beneficiaries with serious illness, we believe it is important and necessary for CMS to engage with the provider community to tackle this question.

AAHPM recognizes that accurate risk adjustment and benchmarking is a critical component of successful model implementation. At the same time, we also believe AAHPM should have the opportunity to pursue this aspect of the model with CMS, should PTAC agree that the overall parameters of the model sufficiently meet criteria to recommend implementation to the Secretary, and we agree that such recommendation should come with the condition that appropriate risk adjustment strategies are finalized prior to implementation. Should PTAC move forward with such a recommendation, AAHPM commits to working with CMS to address this critical challenge.

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<sup>49</sup> NORC at the University of Chicago. HCIA complex/high-risk patient targeting: Third annual report. NORC at the University of Chicago. 2017. Retrieved at: <https://downloads.cms.gov/files/cmml/hcia-chspt-thirdannualrpt.pdf>. Accessed November 6, 2017.

**17. The proposed payment methodology proposed a 20 % reduced monthly PACSSI payment for facility-based payments. Please tell us how the 20% reduction was derived.**

The average number of palliative care visits that can be done in a day in a facility setting is more than at a home setting. Typically, 6-7 palliative care visits occur in a skilled facility versus 4-5 visits in a home setting. This is because patients are co-located in a facility, and there is additional support from nursing, social work, and rehabilitative services (e.g. physical and occupational therapy). Visits are typically longer in a home setting compared to a facility,<sup>50</sup> often due to safety assessments, and travel time is not reimbursed. This is reflected in Medicare Part B, where Evaluation and Management codes have a higher reimbursement in the home setting versus the nursing home setting. Many of the services that need to be brought into a home setting are readily available in the nursing facility. Other services that are needed in the home setting, such as Meals on Wheels, nursing aides, home health, and medication management, are not needed in the facility setting. In a recent time and motion study conducted in a palliative care setting, a significant amount of time is spent in coordination of care;<sup>51</sup> this is especially true in a home setting.

We estimate this number is approximately 20%, however we will look for data within the first two years of the demonstration to determine whether this number is accurate.

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<sup>50</sup> California Healthcare Foundation Up Close: A Field Guide to Palliative Care Retrieved from: <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/PDF%20U/PDF%20UpCloseFieldGuidePalliative.pdf>

<sup>51</sup> Bhavsar Nrupen A., Bloom Kate, Nicolla Jonathan, Gable Callie, Goodman Abby, Olson Andrew, Harker Matthew, Bull Janet, and Taylor Donald H. Jr. *Journal of Palliative Medicine*. October 2017, 20(10): 1120-1126.

**18. Please clarify if the patients' primary and specialty care providers can continue to bill for E&M visits under the PACSSI model.**

Yes, patients' primary and specialty care providers can continue to bill and receive payment for any services provided to patients enrolled in the PACSSI model as they can absent the model, with the exception of chronic care management (CCM) and complex chronic care management (CCCM) codes, as discussed under Question 3 above and Question 19 below. As such, they would be able to bill and receive payment for E&M visits provided to PACSSI patients.

**19. Please clarify if the patients' primary and specialty care providers can continue to bill for Chronic Care Management and Complex Chronic Care Management under the PACSSI model. If not, how will the patients' primary and specialty care providers be informed of this?**

As specified in Question 18 above, patients' primary and specialty care providers will not be paid for CCM and CCCM services for patients enrolled in PACSSI. This restriction is consistent with requirements under the Medicare FFS program that specify that only one practitioner may be paid for these services for a given patient for a given month.

As part of the care planning process, PCTs will be responsible for collecting information from patients on all of their primary care providers and primary treating providers. PCTs will then reach out to these identified providers in order to ensure that:

- The PCTs have full information about patients' health status, treatment, and ongoing management needs.
- The providers are informed of patients' participation in PACSSI, including related restrictions on billing and payment for CCM and CCCM services.
- The providers are engaged in the development and ongoing management of patients' care plans.
- The PCTs are informed of any changes in patients' health status or treatment plans.

PCTs would have a uniform written description of the PACSSI model, including what primary care and specialty care providers may expect as a result of their patients' participation in PACSSI – including restrictions on CCM and CCCM billing – that PCTs would provide with their initial outreach.

AAHPM expects that PCTs will be in close contact with patients' primary and specialty care providers as they manage patients' care.

**20. Page 9 states:**

***“To the extent that practice sizes and caseload are insufficient to achieve reliable quality performance results for a given practice for one or more measures, application of quality performance may be adjusted to ensure meaningful assessment and appropriate payment. Options may include, but are not limited to: formation of voluntary virtual groups among PCTs, assignment of PCTs to designated virtual groups, or assignment of average performance ratings to the PCT.”***

**Please explain “assignment of PCTs to designated virtual groups,” and “assignment of average performance ratings to the PCT.”**

Small caseload and insufficient samples sizes present challenges in the measurement of quality performance that are well known. To address these challenges, the proposal identified potential options for CMS to consider for addressing quality measurement for small PCTs with insufficient sample size, should PTAC recommend the model for implementation to the Secretary.

With respect to assignment of PCTs to designated virtual groups, this option was intended to address potential grouping by CMS of PCTs by some factor (for example, region, PCT characteristics, random selection) for the purposes of collective quality measurement.

With respect to assignment of average performance ratings, this option was intended to assign a performance rating to a PCT on a measure consistent with average performance across a specified subset of PCTs to be determined.

While AAHPM provided these potential options for addressing small sample size, we do not believe that they are exhaustive, nor does the Academy recommend a single option above the others at this time. Further, while it remains a priority for AAHPM to provide opportunities for small practices to participate in models that increase the availability of palliative care for patients across the county, AAHPM believes it is unlikely that most PCTs will have insufficient sample size to require such workarounds to be implemented since most measures will reflect participation across each PCT’s entire PACSSI patient population. We believe it will be important for PCTs have the capacity to accommodate minimum patient volume in order to ensure validity of quality and cost measurement under the model.

AAHPM looks forward to the opportunity to engage with CMS on this issue as needed, should PTAC recommend PACSSI to the Secretary.

**21. The proposal states on p 16 that, “Additional waivers may also be considered, for example regarding fraud and abuse.” Please provide more information on the fraud and abuse waiver that you believe may be necessary to implement this payment model.**

AAHPM recognizes that determining the need for waivers of statutory and regulatory requirements may require complex legal analysis, while also noting that other CMMI models have included fraud and abuse waivers. These waivers revolve around self-referrals, kickbacks, and beneficiary inducements, as examples. Additional details on waivers issued to date can be found at this link: <https://www.cms.gov/Medicare/Fraud-and-Abuse/PhysicianSelfReferral/Fraud-and-Abuse-Waivers.html>

Language regarding potential fraud and abuse waivers was intended to cover the potential need for waivers similar to those issued for other models, in the case that the Department of Health and Human Services determines such waivers are necessary. However, to the extent that fraud and abuse waivers are needed, we believe that this model would require waivers similar to those that have already been approved in other instances and would present a situation that CMMI could readily address.

## Questions about care coordination and integration:

Please provide more detailed description of how PCTs will interact with the patients' primary care providers and specialists, including:

### 22. Do primary care and specialty care providers have a role to play in palliative care under PACSSI? If yes, please describe their role in palliative care distinct from that of the PCT.

Yes, primary care and specialty care providers will play an essential role in palliative care under PACSSI. Patients with serious illness can experience palliative care needs from the time of diagnosis through end of life, often first arising while being cared for by a primary care or specialty care provider. These palliative care needs may include management of pain and other physical symptoms associated with their illness and its treatments, psychological stress and anxiety, loss of ability to function at work and home, concerns about caregiving and the burden it places on their loved ones, spiritual distress surrounding the progression of their illness and its uncertainty for their future, and others.

Some patients' palliative care needs can be first addressed by primary care and/or specialty care providers, who may provide pain and symptom management, advance care planning, and psychological and emotional assessment and support. As the number of aging and seriously ill Americans grows, the importance of delivering palliative care services across the care continuum is rising as a priority among many stakeholders. In fact, an increasing number of physician specialty societies have published guidelines calling for their members to integrate palliative care services into routine care, including societies representing oncology<sup>52</sup>,<sup>53</sup> cardiology,<sup>54</sup> neurology,<sup>55</sup> pulmonology and critical care,<sup>56</sup> and others.

While we applauded these efforts, we also know that many patients' palliative care needs will exceed the capacity, availability or expertise of their primary care or specialty care providers. This is especially true as serious illness progresses, and patients experience greater symptom burden and more functional impairment. PACSSI has been structured to close this gap; specifically, to support specialty interdisciplinary palliative care teams to address the palliative care needs that are not or cannot be met by a patient's existing medical teams.

PACSSI is structured to promote coordination of PCT's services with primary care and specialty care providers, whose role in PACSSI will include, but not be limited to:

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<sup>52</sup> Ferrell BR, Temel J, Smith TJ, et al. Integration of Palliative Care into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Update. *J Clin Oncol* 2016; 35:96-11

<sup>53</sup> Roselio S, Blasco I, Jordan K, et al. ESMO Clinical Practice Guidelines: Supportive and Palliative Care. *Ann Oncol* 2017;22 (suppl 4): 100-18

<sup>54</sup> Allen LA, Stevenson LW, Spertus JA. Decision Making in Advanced Heart Failure: A Scientific Statement from the American Heart Association. *Circulation*. 2012;125:1928-52

<sup>55</sup> Palliative and End-of-Life Care in Stroke: A Statement for Healthcare Professionals from the American Heart Association/American Stroke Association. *Stroke* 2014;45:1887-1916.

<sup>56</sup> Truog RD, Campbell ML, Curtis JR, et al. Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College of Critical Care Medicine. *Crit Care Med* 2008;36:953-63.

- Identification of patients' unmet palliative care needs, and referral to the PCT;
- Participation in care plan development with the PCT, specifically providing expertise in: the patient's diagnosis and illness course; past, present and potential future treatment; past or existing knowledge of patient goals and/or advance care planning activities; and knowledge of caregiver needs;
- Ongoing communication with PCT regarding patient course while under PACSSI, including disease exacerbation or improvement, response to treatment, and management of both anticipated and unanticipated care needs;
- Iterative reassessment, with the PCT, for patient's ongoing appropriateness for PACSSI services, including progression to hospice eligibility and readiness

As noted in pp. 7-8 of the proposal and referenced in the answer to 2b above, the PACSSI service requirements stipulate that PCTs actively communicate with primary and specialty care physicians to ensure that services remain consistent with a care plan that is updated to reflect patients' changing needs. Many PCTs who would participate in PACSSI have already developed strong and mutually beneficial relationships with primary and specialty care physicians and practices whose patients benefit significantly from their services. We anticipate that PACSSI will enable many more such relationships to grow and flourish.

**23. Page 7 of the proposal states:**

***In order for the PCT to receive the PACSSI payment for an eligible patient, and in order for the patient to benefit from the enhanced services available through the payment, the patient would need to:***

- ***Designate the PCT as the patient's primary provider of care management services and palliative care services, in coordination with primary care and/or primary treating providers;***

**What does it mean for the PCT to be the “primary provider of palliative care services?” (Emphasis added.) How will the lines of responsibility be agreed upon and communicated to all treating providers and to the patient? How do you expect patterns of care to change across primary, specialty and PACSSI providers?**

The PCT becomes the *primary* provider of palliative care services when a beneficiary enrolls in PACSSI, and the PCT becomes accountable for their care. As noted in the answer to 22 above, this most often occurs when the beneficiary's palliative care needs (i.e. symptom burden and functional decline) progress to exceed the capacity, availability or expertise of their existing providers. For PACSSI-eligible beneficiaries who do not have strong primary care or specialty care relationships, the PCT may step in directly as the sole provider of palliative care and care coordination services. As noted in foregoing answers, PACSSI payments will replace any care management (i.e. CCM and CCCM) payments for any providers caring for an enrolled beneficiary, which acknowledges that the PCT will be the primary provider of these services.

Many PACSSI-enrolled beneficiaries will have engaged primary care and specialty care providers, and will continue to receive services while enrolled in PACSSI. In fact, one of the fundamental purposes of the PACSSI model is to enable patients with serious illness to receive community-based, interdisciplinary palliative care services while also being treated, as appropriate, by their primary care or specialty providers. For example, a patient with advanced cancer receiving PACSSI services may also be receiving chemotherapy or radiation therapy from their oncology provider; or a patient with advanced congestive heart failure may be receiving care from a primary care and/or cardiology provider to optimize medication management and maximize function.

AAHPM also expects that PACSSI-enrolled patients may continue to receive some primary palliative care and supportive services (as described in question 22 above). We further expect the lines of responsibility for palliative care services to be established through the collaborative care plan development and ongoing communication requirements in the model. Through these mechanisms, PCTs will work iteratively with primary and specialty providers to clearly identify which services will most benefit the patient and caregiver, and who may best deliver them.

For example, a patient with advanced cancer will often have their palliative care needs first addressed by their oncologist and perhaps primary care provider, who will assess and treat pain and other symptoms, provide emotional support during diagnosis and treatment, and

explore advance care planning. The primary oncologist and/or primary care provider will provide these services through a combination of office visits and care management services delivered between visits, to meet the patient's needs. As the patient's cancer progresses, increasing symptom burden and functional decline may make it more difficult for the patient to have their needs met at home with existing care management support, leading to emergency department and unplanned hospital admissions. The PCT can then assume primary responsibility for palliative care services – delivered primarily at home – and still coordinate with the treating providers to understand disease progression, any cancer treatment options that could support patient goals, and other factors that inform prognosis and help anticipate care needs.

PACSSI services can also help the primary care and specialty care providers by delivering valuable services to their seriously patients – like home-delivered advanced symptom management, psychological support or spiritual care – that may not themselves have the infrastructure or capacity to deliver. The coordination and communication requirements described in the answers to 2b, 22 and 23 above, will ensure that PCTs are actively engaging with primary and specialty care providers to maximize the value of this care.

This example of collaboration allows primary and specialty care providers to work with PCTs to collaboratively meet the holistic needs of patient and caregivers, throughout the course of serious illness. The specifics of collaboration among primary care providers, specialty care providers and PCTs will be unique to each individual beneficiary's needs, and the PCTs accountability for patient and caregiver experience (as described in our discussion of quality measures above) will incentivize the PCT to ensure that collaboration remains fully patient-centered.

**24. Page 3 of the proposal states, “PCTs would work in collaboration with the full spectrum of primary and specialty care clinicians to develop and execute a care plan consistent with patients’ needs and preferences.” How would PCTs work with patients’ primary and specialty care providers to develop and execute this plan? Is there a standard protocol to be followed? How will the model ensure high quality care coordination and integration?**

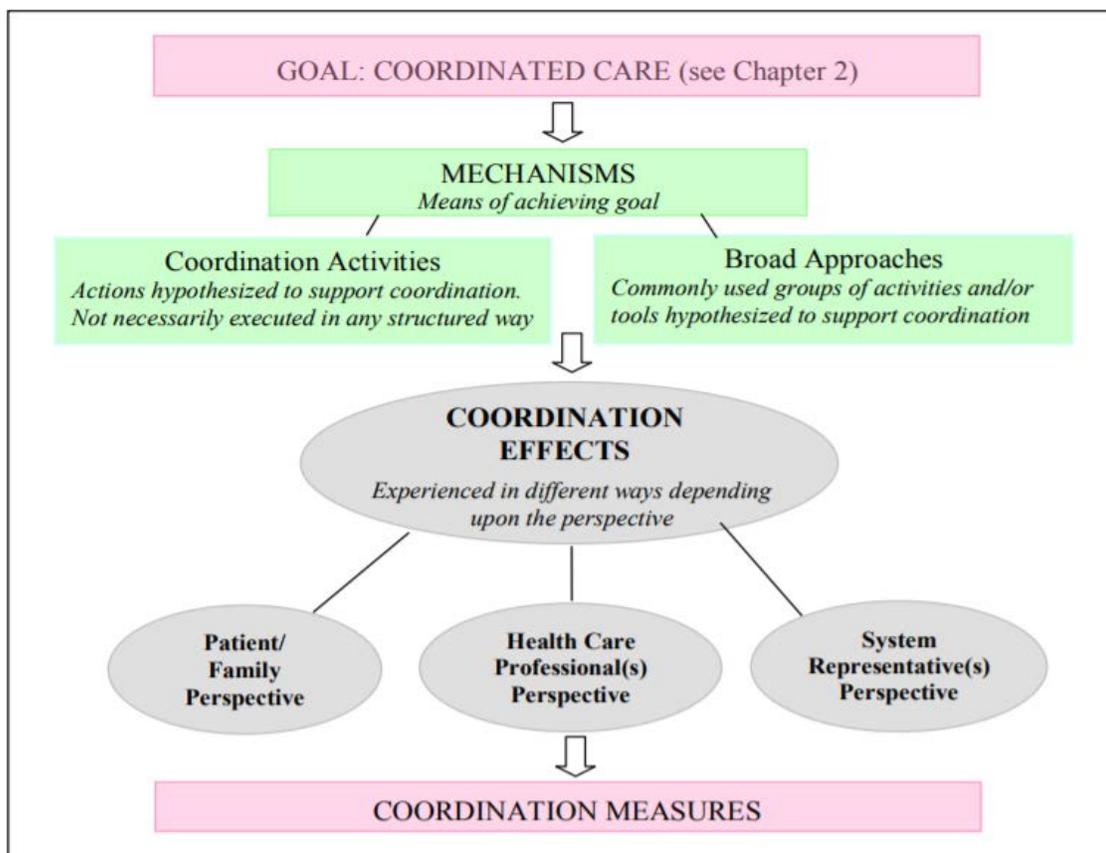
PCTs would communicate and collaborate with primary and specialty clinicians in a number of ways, some referenced in the responses to questions 2a, 2b, 22 and 23 above. The PACSSI model was created explicitly to allow PCTs to deliver services that support and complement primary and specialty care, which establishes an expectation of collaboration. This includes collaborative development and execution of care plans consistent with patient needs and preferences. The process of collaborative care planning requires input from the primary and/or specialty care clinicians regarding diagnosis, optimal disease-oriented care and likely outcomes, prognosis, and initial palliative care assessment and interventions. It also requires input from the PCT regarding patient and caregiver “next level” physical, psychological, practical and spiritual needs, as well as service deliverables in the home setting. When executed well, this collaborative approach allows each team to provide its key expertise in service of meeting patient and caregiver needs.

As PACSSI is a model in development, widely adopted standard protocols for collaborative care planning and execution of community-delivered palliative care do not yet exist. We believe the requirements for coordination and collaboration in the PACSSI model will generate valuable data and experience to inform evidence-based best practices. For example, we would require that a care plan be revised with any significant change in patient functional status or serious illness progression, and that any care plan be developed and communicated among PCT, patient and caregiver, and primary care and/or specialty care providers, if engaged.

High-quality care coordination will be also promoted by the PCTs’ accountability for quality and spending performance. In both PACSSI tracks, PCTs are incentivized both to provide high-quality care coordination, so that patient and caregiver experience is optimized, and to ensure that care delivered is as consistent as possible with achievable patient goals. The payment methodology is explicitly designed to drive both outcomes, and thus drive better care for seriously ill patients and their caregivers.

**25. We do not see a proposed measure of care coordination and integration in the list of proposed quality measures/items. How will PACSSI monitor and assess care coordination and integration?**

Care coordination addresses potential gaps in meeting patients’ interrelated medical, social, developmental, behavioral, educational, informal support system, and financial needs in order to achieve optimal health, wellness, or end-of-life outcomes, according to patient preferences.<sup>57</sup> Information flow across providers is especially important at times of transition when responsibilities for care delivery shift from one entity to the next. Care coordination can be measured from 3 different perspectives: patient and family experience of care, the health care professional perspective, and the system representative perspective.<sup>58</sup> The patient/family experience of care survey will capture how well information and collaboration occurred between the different health care teams. From the health care professional perspective, PCTs may develop surveys or outreach tools for the primary care/specialty provider to capture their assessment of care coordination and may also address care coordination challenges and successes through the learning collaborative. Finally, we feel the utilization measures and cost of care will capture the third perspective of system representative. The graph below illustrates the care coordination framework and is obtained from the Care Coordination Measures Atlas referenced above.



<sup>57</sup> Adapted from information published in: Antonelli RC, McAllister JW, Popp J. Making care coordination a critical component of the pediatric healthcare system: A multidisciplinary framework. New York: The Commonwealth Fund; 2009

<sup>58</sup> Care Coordination Measures Atlas, AHRQ Publication No. 11-0023-EF December, 2010

In addition to the measures tied to quality and cost accountability noted above, AAHPM expects additional monitoring and assessment of care coordination and integration would occur through efforts undertaken by the evaluation contractor, as well as through program integrity oversight efforts undertaken by CMS. For example, we anticipate that the evaluation contractor may engage in activities such as site visits, practice surveys, and key informant interviews to determine how PCTs' approach to care delivery changes as a result of the model. This may include interviews with a sample of PCTs and the primary and specialty care providers who refer patients to the PCTs. Further, we anticipate that CMS will engage in monitoring and oversight activities to ensure that PCTs are meeting minimum participation standards, and that CMS will also track beneficiary complaints that may arise from challenges with care coordination.

## 26. To what extent has AAHPM received input from primary and specialty care providers in the development of this proposal?

AAHPM engaged in an transparent and collaborative effort to build a physician-focused payment model that addresses identified gaps in care for patients with serious illness. Development of the PACSSI model began by the Academy first empanelling an Alternative Payment Model Task Force (see roster on p. 22 of our submission). Members were selected for their recognized leadership in key aspects of APM development, including quality measurement and improvement, delivery innovation, novel collaboration and partnerships, and community engagement. These palliative care thought leaders include representatives of palliative care provider organizations, hospices, health systems, and payers serving urban, suburban and rural communities. In addition to their palliative care expertise, many task force members are either experienced in or actively practicing primary or specialty care, including family medicine, general internal medicine, geriatrics, and oncology. The PACSSI proposal was developed with these key perspectives explicitly included in the process.

After several months of research, deliberation, and development, the AAHPM APM Task Force presented the first draft of its proposals to attendees at the February 2017 Annual Assembly of Hospice and Palliative Care (the national annual conference for the field convened jointly by AAHPN and HPNA). This presentation was immediately followed by a roundtable dialogue and question and answer session between Task Force members and representatives from numerous stakeholder organizations.

Based on feedback from those engagements, AAHPM finalized a discussion draft in March 2017. The next month, the draft was posted for review by the Academy's more than 5,000 members, who were invited to provide detailed feedback through an online survey; over 100 members responded with detailed input on priorities, design parameters, expected participation, and more. AAHPM also shared the discussion draft with nearly 20 external organizations to solicit feedback. These included hospice and palliative care stakeholders such as national associations representing other disciplines or entities involved in providing palliative care (nurses, social workers, physician assistants, chaplains, pharmacists, hospice organizations), other medical specialty societies (geriatrics, home care medicine, post-acute and long-term care, clinical oncology), and others. Leading researchers were also consulted to provide data to help refine AAHPM's payment reform proposals. As with member feedback, this input shaped our final submission.

AAHPM continues to be engaged with our colleagues and stakeholders from primary care and specialty care societies and practices, and we anticipate continuing very close collaboration should our proposal be approved for testing or implementation. One of the fundamental goals of PACSSI is to allow patients with serious illness and their caregivers to receive valuable palliative care services alongside their other valuable primary and specialty care. As a result, primary care and specialty care input into design, implementation and refinement will be essential.

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AMERICAN ACADEMY OF  
HOSPICE AND PALLIATIVE MEDICINE

March 16, 2018

Physician-Focused Payment Model Technical Advisory Committee  
c/o U.S. Department of Health and Human Services (HHS)  
Asst. Secretary for Planning and Evaluation Office of Health Policy  
200 Independence Avenue S.W.  
Washington, D.C. 20201  
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**RE: Response to Preliminary Review Team Assessment of the Patient and Caregiver Support for Serious Illness (PACSSI) Alternative Payment Model (APM)**

Dear Committee Members,

The American Academy of Hospice and Palliative Medicine (AAHPM) thanks the Preliminary Review Team (PRT) for its careful deliberation regarding the PACSSI model and appreciates this opportunity to respond to concerns raised in the PRT report.

As you know, AAHPM is the professional organization for physicians specializing in Hospice and Palliative Medicine. Our more than 5,000 members also include nurses and other health and spiritual care providers deeply committed to improving quality of life for patients facing serious illness, as well as their families and caregivers. As such, we are heartened by and thankful for the PRT's assessment that the model's scope – with respect to its focus on serious illness and improved access to palliative care – reflects an unmet need that deserves priority consideration. However, we recognize that the PRT identified several concerns with the model under the Quality and Cost and the Payment Methodology criteria.

As a starting point for our response, we believe it would be helpful to articulate the guiding principles that we applied as we conceptualized and solidified the PACSSI model parameters. These include the following:

- **Principle 1:** An APM for serious illness care should increase access to and ensure **sustainability of high-quality palliative care and hospice services** that improve quality of care and quality of life for patients with serious illness and their caregivers.
- **Principle 2:** To increase access to palliative care services:
  - **2a:** An APM should allow **participation by palliative care teams of many sizes and types, caring for patients throughout the course of serious illness, in many different markets and geographies, and at various levels of risk-readiness.**
  - **2b:** **APM eligibility criteria should identify patients based on need**, rather than arbitrary and flawed estimates of patient prognoses.
- **Principle 3:** The palliative care team structure and service requirements should be provided in accordance with the **National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care.**

- **Principle 4:** Quality measurement and accountability need to **align with the state-of-the-field** (to include measure concepts under [Measuring What Matters](#), an expert consensus project convened by AAHPM and the Hospice and Palliative Nurses Association (HPNA)) and should help advance our understanding of high-quality palliative care.
- **Principle 5: Payment should be sufficient** to cover the cost of delivering care in diverse communities, including rural and underserved urban communities, **without increasing net costs** to the Medicare program. Payment benchmarks should also be accurately risk-adjusted, to avoid exaggerated losses or gains to providers.
- **Principle 6:** The APM development process should be **transparent and inclusive**, with **engagement by a breadth of stakeholders from the serious illness provider community** – including the National Coalition for Hospice and Palliative Care and representatives from other relevant medical specialty societies and provider organizations – to address cross-cutting high-priority concerns.

These principles reflect AAHPM’s belief that an APM must acknowledge existing limitations (for example, with respect to provider readiness and risk tolerance, as well as lack of availability of quality measures and certified electronic health record technology, or CEHRT, that appropriately support palliative care) while also seeking to push the delivery of palliative care ever forward with respect to quality, patient and caregiver experience, availability of services, and value. They are also a testament to the incorporation of the priorities of stakeholders in the field who are at the front lines of advocating for and delivering high-quality palliative care services.

Since we submitted our proposal to PTAC, AAHPM leaders have continued to deliberate internally, as well as with external partners and stakeholders, to consider potential refinements to PACSSI – consistent with the above principles – that could further strengthen the model. At the same time, we recognize that additional work is needed to fully realize these principles, for example, related to risk adjustment and benchmarking. However, we believe that the model – as submitted or with potential refinements – would address significant gaps in care and lead to improvements in experience and outcomes for the nation’s sickest, most vulnerable patients and their families and caregivers and, for that reason, we seek to provide clarifications to the areas where the PRT has expressed concern.

## Quality

The PRT raised several concerns about PACSSI’s quality accountability framework, including that there were insufficient outcome and utilization measures, as well as insufficient monitoring of quality based on the timing of measurement.

AAHPM approached quality measurement and accountability in accordance with principle 4 above, which takes into account the existing state of quality measurement for palliative care, as well as builds on existing consensus-based work on quality measurement to date. As stated in AAHPM’s written response to the PRT’s questions, the patient experience of care surveys are currently in development and are patterned closely after the Hospice CAHPS survey used in the Hospice Quality Reporting Program. Our decision to use these tools was based on palliative care providers’ experience using validated CAHPS surveys, as well as the demonstrated value of the survey measures regarding the quality of care provided to seriously ill patients (as evidenced through the use of the Hospice CAHPS survey).

The proposed surveys include items similar to the 29 patient-reported or caregiver-reported outcome items in the Hospice CAHPS, grouped in the following domains:

- Team communication;
- Getting timely care;
- Treating family members with respect;
- Providing emotional support;
- Getting help for symptoms;
- Getting personal care training;
- Providing support for religious and spiritual beliefs;
- Information continuity;
- Understanding the side effects of pain medication;
- Overall rating of care; and
- Would you recommend the palliative care team to family/friend.

The patient experience of care surveys in development also include additional items on the quality of communication with the palliative care team, including:

- Whether the information was presented in a way the person could understand;
- Whether the health care professionals communicated in a sensitive manner;
- Whether the seriously ill person and family were allowed to ask questions; and
- Whether they were able to make a decision without feeling pressured by the health care team to make a decision that they did not want.

We note that several symptom-based outcomes are included in the survey under the “Getting help for symptoms” domain, including pain, trouble breathing, constipation, and anxiety or sadness. And while the PRT suggests that the remaining survey measures do not reflect outcomes, we note that palliative care is whole-person care intended to support a better serious illness experience overall, not just symptom management. As such, the patient and caregiver experience measures included in the survey reflect important outcomes of care for this population. Indeed, in the development of the Hospice CAHPS survey, interviews and focus groups with caregivers of hospice patients led the survey development team to focus on items included in the above domains,<sup>1</sup> suggesting that they are the outcomes caregivers most highly prioritize.

We also note that most palliative care teams are not routinely collecting patient-reported outcomes outside of patient experience of care surveys. This includes the PROMIS measures the PRT referenced, which have not been tested and validated for this patient population. As such, mandating collection of such patient-reported outcomes would pose a barrier to recruitment of palliative care teams of varying sizes, types, locations and levels of risk tolerance, in conflict with principle 2a above. Additionally, the PRT did not acknowledge that the utilization measures also measure outcomes of care, including enrollment in hospice and avoidance of days in an intensive care unit (ICU).

With respect to measurement timing, AAHPM sought to balance the need to monitor quality against the burden imposed on palliative care teams (PCTs) and, more importantly, on patients and their caregivers, who – by virtue of their eligibility for the model – already would be experiencing significant pain and suffering and who would be balancing numerous demands on their time, as well as on their physician, mental, and emotional resources.

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<sup>1</sup> Price RA, Quigley DD, Bradley MA, et al. (2014). *Research Report: Hospice Experience of Care Survey – Development and Field Test*. Sponsored report by the Rand Corporation on behalf of CMS.  
[https://www.rand.org/content/dam/rand/pubs/research\\_reports/RR600/RR657/RAND\\_RR657.pdf](https://www.rand.org/content/dam/rand/pubs/research_reports/RR600/RR657/RAND_RR657.pdf)

AAHPM also considered the addition of further utilization measures tied to accountability but declined to do so due to potential concerns about the incentives that could be created to stint on care. However, AAHPM specified that utilization measures should be included in the evaluation of the model.<sup>2</sup>

That said, AAHPM is open to including additional evidence-based measures in the quality accountability framework as the model development process progresses and would appreciate the opportunity to continue refining the model, should PTAC vote to recommend the model for testing or implementation. Further, palliative care teams may use a variety of instruments to complete processes of care, including the comprehensive assessment, as appropriate for their settings, patient populations, and clinical workflows. These instruments could also assess patient-reported outcomes and contribute to the expansion of available measures for future incorporation into the PACSSI accountability framework.

## Payment Reforms

The PRT raised concerns about the complexity of the payment reforms with multiple tiers and multiple tracks, the potential for patient selection and gaming, the lack of a minimum savings or loss rate, and the savings/loss sharing structure, including the asymmetric nature of the risk.

AAHPM established multiple tiers and multiple track under PACSSI to ensure that (1) practices at different levels of readiness and risk-tolerance could participate, while also allowing for greater risk and reward for more advanced PCTs (see principle 2a), and (2) payments would be sufficient to cover the costs of delivering high-quality care, particularly when practices treat high-complexity patients (see principle 5). Indeed, AAHPM views the flexibility provided under the model as a strength rather than a weakness and notes that several other models developed and implemented by the Centers for Medicare & Medicaid Services (CMS) exhibit far greater complexity (for example, the Comprehensive Primary Care Initiative Plus, which includes up to five payment tiers and two tracks while also providing for partial capitation payment in the second track, or the Medicare Shared Savings Program (MSSP), which includes three tracks with different risk sharing arrangements). As such, we do not believe that model complexity should deter PTAC members from voting in favor of PACSSI.

With respect to the risk structure, we believe that current models bear witness to the fact that models do not need to have symmetrical risk to warrant testing, provided that best estimates of the models' cost or savings impacts suggest at least cost-neutrality with improved quality outcomes by the end of the model testing period (consistent with criteria included in the Affordable Care Act for CMS Innovation Center models, which do not require cost-neutrality at the outset of the model). MSSP and the Oncology Care Model, for example, both include tracks that allow only one-sided risk with large potential for upside savings. However, even under PACSSI Track 1, which is targeted for smaller PCTs or those working in rural areas who are less able to take on risk, the PACSSI model includes accountability tied to care management revenues for performance on both quality and cost.

Additionally, we would point out that Track 1 specifically includes a minimum savings/loss rate, as noted on page 15 of our proposal: "To meet the spending benchmark, total cost of care for enrolled patients (including PACSSI care management payments) must be below risk-adjusted predicted spending levels, where such predicted spending levels include a point estimate plus or minus 4 percent. This +/-4.0

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<sup>2</sup> See page 18, which states: "This evaluation will be based on the quality and cost accountability structure built into the PACSSI model. Additionally, for those patients who are enrolled in PACSSI and who die during a performance year, performance can be assessed on outcomes such as hospice length of stay, days in the intensive care unit, emergency department visits, and hospital admissions in the last year of life."

percent is intended to serve as a minimum loss rate to account for potential variation in spending due to small sample sizes and chance.” Appendix 7 also notes: “Total cost of care benchmarks would be subject to a +/-4.0 percent minimum loss rate to account for potential variation in spending due to small sample sizes and change under Track 1. A similar minimum loss rate could also be applied in Track 2.”

As with quality measurement and accountability, however, AAHPM believes that refinements to the payment reforms included in the model could potentially strengthen the model, and we notes that -- even under the submission – we presumed that further refinement would be necessary. (As indicated by its title, Table 5 simply provides an illustrative example of what a shared savings/loss structure could look like.) We believe engagement with CMS will be necessary to finalize the financial accountability structure under the model in a manner that still adheres to the above guiding principles.

## Service Delivery Reforms

The PRT raised concerns about care coordination under the model, including regarding how PCTs would work with primary care providers, and also noted the need for more patient- and family-centeredness with respect to care planning and shared decision-making. The PRT further noted the potential for variation in the qualifications among PCTs and minimal standards for contact with beneficiaries.

AAHPM established its service delivery reforms, including PCT structure and patient engagement, consistent with principle 3 above, and notes that the [NCP Guidelines](#) reflect a rigorous standard of care for patients with serious illness. The Guidelines address care across eight domains, including:

- Structure and Process of Care.
- Physical Aspects of Care
- Psychological and Psychiatric Aspects
- Social Aspects of Care
- Spiritual, Religious, and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Patient at the End of Life
- Ethical and Legal Aspects of Care

We believe that the approach laid out in the NCP Guidelines and adopted under PACSSI addresses the concerns raised by the PRT. For example:

- Guideline 1.2 notes that “The care plan is based on the identified and expressed preferences, values, goals, and needs of the patient and family and is developed with professional guidance and support for patient-family decision making. Family is defined by the patient.”
- Guideline 1.8 notes that “Community resources ensure continuity of the highest quality palliative care across the care continuum.” This guideline specifies that “Hospice programs, non-hospice palliative care programs, and other major community service providers involved in the patient’s care, establish policies for formal written and verbal communication among and between clinicians involved in the patient and family’s care” and that “policies enable timely and effective sharing of information among health care teams while safeguarding privacy.”

## Evaluation and Benchmarking

The PRT expressed concerns about the difficulty in establishing spending benchmarks and in building valid comparison groups as a result of enrollment bias and lack of data in administrative data sets. In establishing the framework for evaluation and benchmarking, however, AAHPM relied on principle 2b above, which

prioritizes patient eligibility based on need. While we recognize that needs-based assessment that incorporates functional data not included in administrative data sets complicates both the calculation of benchmarks and the identification of comparison groups, functional status is a key indicator of palliative care needs that must be included in the determination of patient eligibility to target the appropriate patient population.

We also recognize the need for accurate risk-adjustment in benchmarking and evaluation, as specified in principle 5, particularly for this high-risk population. We reiterate our position (as stated in the response to PRT questions) that it is important and necessary for CMS to be involved in the development of a benchmarking and risk adjustment methodology, given its access to data and extensive expertise in model operations and evaluation. As such, we urge PTAC members to recognize the need to advance the model to promote CMS engagement in this important work.

## Conclusion

AAHPM appreciates the opportunity to provide the above clarifications regarding our guiding principles in developing the PACSSI model, the ways those principles affected our decision-making regarding model parameters, and the impact of the model in driving high-quality, high-value care. At the same time, we urge PTAC members to recognize that many of the model elements can only be refined through close collaboration with CMS (relying on CMS's data, analytic capabilities, and expertise) and through on-the-ground testing, and that such testing is warranted given the significant need and critical gaps in care that PACSSI could address. We note that the model as submitted reflects the input and support of a wide range of stakeholders involved in and committed to palliative care, which speaks to both the building momentum for action in this area and the recognition that PACSSI presents a compelling opportunity to channel that energy. We ask that the full Committee consider these factors as it deliberates and votes on the PACSSI model, and we look forward to that upcoming engagement.

If you have any questions, please contact AAHPM Director of Health Policy and Government Relations Jacqueline M. Kocinski, MPP, by phone at 847.375.4841 or by email at [jkocinski@aahpm.org](mailto:jkocinski@aahpm.org).

Sincerely,



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President

American Academy of Hospice and Palliative Medicine