

MEASURE APPLICATIONS PARTNERSHIP

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Performance  
Measurement  
Coordination  
Strategy for Hospice  
and Palliative Care

FINAL REPORT

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NATIONAL  
QUALITY FORUM

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## EXECUTIVE SUMMARY

People in the U.S. have a variety of experiences within our nation's health system. Some of us interact with the health system during life's most joyful times—like the birth of a child—and some of the most difficult, including serious illness or loss of life. Others may choose to spend that time under the watchful eye of hospice or palliative care which are alternative ways to have a patient's full range of emotional, biomedical, and spiritual needs met; have personal choices honored; have families and patients equally supported; and experience the same outcome for less medical intrusion and cost.

Hospice was formalized as a Medicare benefit in 1982. It first took root in lock step with cancer care but has now been embraced by people with a variety of terminal illnesses. Enrollment in hospice programs has risen 50% in the last decade; demographical trends speak to a possible increase in services as the American population ages. Palliative care—which seeks to optimize quality of life by facilitating patient choice, autonomy, and access to information—can be provided within and beyond hospice programs, and in connection with disease-modifying therapy that has curative intent.

Under law, as part of the new Medicare Hospice Quality Measurement Program, hospice programs will be required to publicly report quality data to the federal government beginning in 2014 or incur a financial penalty. While there is not a formal quality reporting program for palliative care, settings in which palliative care is provided (e.g., hospitals, home health) are required to participate in federal quality initiatives. The new hospice reporting program along with other federal quality initiatives are part of a concerted push to bring performance measurement and public reporting into all corners of healthcare, as we strive to meet national aims of healthier people, better care, and more affordable care.

This increased measurement focus, in addition to the growth of providers offering hospice and palliative care, creates impetus and opportunity for developing a performance measurement strategy for these services. In turn, a well-designed measurement roadmap could ensure that efforts in the public and private sector are synchronistic, and that appropriate focus is put on measures that can make the biggest difference in improving hospice and palliative care from the patient's perspective.

The Department of Health and Human Services (HHS) turned to the Measure Applications Partnership (MAP) to help inform this strategy. MAP is comprised of 60 organizations representing diverse stakeholder interests. It was convened in 2011 by the National Quality Forum (NQF) to provide guidance on measures for use in performance-based payment, public reporting, and other quality improvement programs in both the public and private sectors. This report is the 7th in a series of reports authored by MAP in its advisory role to HHS, and is the first to focus on a particular healthcare service area. Related, in February 2012, MAP provided input on an initial set of measures under consideration for hospice public reporting in its inaugural pre-rulemaking report, [Input on Measures Under Consideration by HHS for 2012 Rulemaking](#).

This report builds on MAP's pre-rulemaking deliberations to present a prioritized set of 28 highly-prioritized measurement opportunities, more than a dozen existing measures ready for immediate application in the new Medicare Hospice Quality Measurement Program, and a range of measures that can be adapted to palliative care settings. Taken together, these measures would begin to offer the kind of data sought by patients and the healthcare field at large.

Improving hospice and palliative care will advance two significant priorities of the National Quality Strategy—person- and family-centered care, and care coordination. Effectively delivered, these services move the healthcare system toward a different model where the emotional, spiritual, social, and psychological needs of patients are just as important as their physical needs, and are met with a cohesive, team-based approach.

Recognizing that measurement in this area is new, MAP suggests a phased approach that emphasizes clinically-focused measures at first, but quickly expands to more measures that follow the patient and their full set of experiences rather than the setting or fragments of a patient's care (often referred to in this report as 'cross-cutting'). Measurement should also quickly scale to capture non-clinical measures of care delivery with emphasis on the following areas:

- **Access and Availability of Services.** MAP notes that while enrollment in hospice continues to increase, the average length of stay is still relatively brief with the majority of people utilizing the Medicare Hospice Benefit for less than six weeks. New measures could signal when a patient and their family has been made aware of these services. Measures could also assess the timeliness of care once a patient has decided to receive hospice or palliative care.
- **Person- and Family- Centered Care.** Measures could help assess the spiritual, physical, and psychological aspects of care; the patient's and family's experiences of care; physical aspects of

care such as managing anxiety or delirium; and if family goals are met.

- **Goals and Care Planning.** Many patients and families outline their goals for hospice and palliative care, and develop a "care plan" which specifies their preferences. Measures could be installed to assess whether these goals and plans have been established and honored.
- **Care Coordination.** Hospice and palliative care, like many other kinds of care, often extend beyond one setting. For example, a patient may start in a nursing home, be transferred to a hospital for an acute event, and eventually move home. All of these hand-offs require careful planning and coordination between caregivers. Measures can help track breakdowns that occur during these transitions, such as tracking patients' goals, transfer of complete medical records, and communication.
- **Provider Competency.** Measures can help offer assurance that the patient and family is cared for by a qualified healthcare team that is trained to provide hospice and palliative care, as well as determining if providers are given the education they need to do their job well.
- **Appropriateness/Affordable Care.** A key tenet driving patient choice of hospice is avoidance of unwanted trips to the hospital or unwanted medical procedures. Measures can help assess these dimensions.

This performance measurement strategy holds much promise in improving the hospice and palliative care arena, but there are obstacles in achieving it more immediately. First, measurement gaps exist—meaning the measures that may matter most do not yet exist, or need to be refashioned to meet these needs. New measures could also help better understand any unintended consequences of new measurement and public reporting requirements. MAP's hope is to engage the measure development community to meet these priorities and fill these gaps. Second,

given the many hand offs between settings, the desire for personalized care in settings such as the home, and to capture patient experience through the vantage point of the patient themselves, MAP encourages further investments into data infrastructure and health information technology applications. Lastly, MAP stresses the importance of the patient in developing and implementing this new strategy. Capturing the patient and family voice is an essential building block for any successful, fully integrated hospice

and palliative care performance measurement coordination strategy. Every voice is unique; every experience may offer the field valuable insight as hospice care continues to evolve. Learning how to more systemically capture and channel patient experience into the field of performance measurement continues to be a challenge, but one that offers great hope in helping to better understand this critical area of the healthcare system.

## INTRODUCTION

The Measure Applications Partnership (MAP) has been charged with developing a performance measurement strategy for hospice and palliative care. **Hospice** is a Medicare benefit that provides palliative care for patients who are in the last six months of a terminal illness and require comprehensive biomedical, psychological, and spiritual support. Hospice also provides support to family members coping with the complex consequences that are associated with illness as death nears, and addresses the bereavement

needs of the family after the death of the patient.<sup>1</sup> **Palliative** care should be provided well in advance of the final stages of an illness and seeks to optimize quality of life by addressing physical, psychological, emotional, social, and spiritual needs throughout the illness trajectory and by facilitating patient autonomy, choice, and access to information.<sup>2</sup> Palliative care can be provided at any point in a patient's life, within and beyond hospice programs.

**FIGURE 1. HOSPICE AND PALLIATIVE CARE ALONG THE CONTINUUM OF CARE**



Figure 1 depicts hospice and palliative care along the trajectory of illness. Palliative care can occur in collaboration with disease-modifying therapy that has curative intent, while hospice care occurs once a physician determines that the patient will likely not survive past six months and the patient decides to cease curative therapies. Hospice also supports family members with bereavement, after the death of the patient.

Enrollment in hospice programs has risen by more than 50 percent during the past decade,<sup>3</sup> increasing attention to this option for end-of-life care. Hospice increases value in healthcare by honoring patients' preferences to forego unwanted procedures, hospitalizations, and other, often costly, services. Patients in hospice often choose to stay in their homes and thereby avoid expensive medical care they would otherwise have undergone in other settings.<sup>4</sup> This is particularly salient for high-cost populations such as dual eligible beneficiaries and people with multiple chronic conditions. Providing palliative care options to individuals improves healthcare outcomes, such as increasing their quality of life based on their goals of care, effectively coordinating their care, and reducing unwanted and often unnecessary procedures.<sup>5</sup> Evidence also indicates that both hospice and palliative care may increase a patient's longevity and lower costs.<sup>6</sup>

As for all care, performance measurement is essential to continually evaluate whether the care provided is appropriate, high quality, patient-centered, and effectively coordinated across providers. Both hospice and palliative care often occur across multiple settings: home, nursing home, assisted living facility, clinician office, hospital, and others. The average Medicare hospice enrollee is in the home for 56 percent of the time, but also is in an assisted living facility for 11 percent of the time and a nursing home for 17 percent of the time.<sup>7</sup> Additionally, the patient population has shifted in the past decade, moving from being

primarily cancer patients to patients with varying diagnoses such as dementia, respiratory problems, and Parkinson's disease.<sup>8</sup> A well-coordinated system of care, centered on patients and families and their needs, is the goal for effective hospice and palliative care.

Publicly reporting performance measurement information for hospice care providers is new. Section 3004 of the Affordable Care Act directs the Department of Health and Human Services (HHS) to establish reporting requirements for hospice programs. In fiscal year 2014, hospice programs will be required to submit quality data or incur a financial penalty. MAP's role is to provide input on performance measures for hospice care with an eye toward alignment of measurement across various settings. In its inaugural pre-rulemaking report, [Input on Measures Under Consideration by HHS for 2012 Rulemaking](#), MAP provided input on an initial set of measures under consideration for hospice public reporting, noting that performance measurement in this program needs to expand beyond clinically focused measures to address all aims and priorities of the National Quality Strategy (NQS). Recognizing that hospice and palliative care are holistic approaches inextricably connected on the continuum of care, MAP provides input on high-leverage measurement opportunities and specific measures that address both hospice and palliative care in this report. MAP also recognizes opportunities to enhance measurement by identifying measure gaps where measures are not currently available.

## APPROACH

MAP is a public-private partnership convened by the National Quality Forum (NQF) for the primary purpose of providing input to HHS on selecting performance measures for public reporting, performance-based payment, and other programs (Appendix A—MAP Background). The statutory authority for MAP is the Affordable Care Act (ACA), which requires HHS to contract with a consensus-based entity (i.e., NQF) to “convene multi-stakeholder groups to provide input on the selection of quality measures” for various uses.

The multi-stakeholder, 22-member MAP Post-Acute/Long-Term Care (PAC/LTC) Workgroup advised the Coordinating Committee on identifying measures for quality reporting for hospice programs and facilities and for palliative care (see Appendix B for the workgroup roster and Appendix C for the Coordinating Committee roster). The workgroup held one in-person meeting and one web meeting to finalize the high-leverage measurement opportunities and to identify existing measures for application and measure gaps. The agendas and materials for the PAC/LTC Workgroup meetings can be found on the [NQF website](#).

To inform planning for the PAC/LTC Workgroup meetings and the development of this report, NQF provided the workgroup with background information gleaned from existing studies and reports on hospice and palliative care. The following were fundamental in shaping this work:

- *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*, a 2006 NQF consensus report that provides a comprehensive landscape of hospice and palliative care quality measurement efforts and presents 38 preferred practices.<sup>9</sup>
- *National Voluntary Consensus Standards: Palliative Care and End-of-Life Care*, which reports on the results of the evaluation of 22 measures submitted for endorsement under NQF’s Consensus Development Process.<sup>10</sup>

- *Input to the Secretary of Health and Human Services on Priorities for the 2011 National Quality Strategy and the Palliative Care and End-of-Life Care Convening Meeting-Synthesis Report*, two efforts of the National Priorities Partnership (NPP) that explore priorities and strategic opportunities to address palliative care.<sup>11,12</sup>
- *Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value* published in the *Milbank Quarterly*, which offers perspectives on ways to improve the delivery of hospice and palliative care.<sup>13</sup>

The PAC/LTC Workgroup members developed priority measurement opportunities for hospice and palliative care during their in-person meeting and further refined this list through a subsequent survey and web meeting. The workgroup process identified 28 high-leverage measurement opportunities for both hospice and palliative care (see Table 1). The establishment of these measurement opportunities led to the identification of clinical quality and patient-centered cross-cutting measures for the Medicare Hospice Quality Reporting Program and for palliative care across settings, including measures for both immediate application and further exploration. To support the identification of measures, NQF staff conducted a scan of NQF-endorsed measures and measures in the development and endorsement pipeline that could potentially address the highly prioritized measurement opportunities for hospice and palliative care. Moreover, the process of identifying measures highlighted gaps in available measures, prompting discussion on a strategy for addressing the gaps. Finally, the workgroup revisited the MAP data platform principles (see MAP [clinician](#), [safety](#), [dual eligible beneficiaries](#), and [PAC/LTC](#) performance measurement coordination strategy reports) to identify data considerations specific to hospice and palliative care.



## HIGH-LEVERAGE MEASUREMENT OPPORTUNITIES

In considering the continuum of hospice and palliative care, MAP established high-leverage measurement opportunities, noting that performance measures must recognize an approach to care that is holistic, team-based, and patient- and family-centered. As MAP has signaled in its previous performance measurement coordination strategies (see MAP [clinician](#), [safety](#), [dual eligible beneficiaries](#), and [PAC/LTC](#) reports), setting-specific silos inhibit care coordination and aligned performance measurement. Many of the existing performance measures for hospice are condition specific (e.g., cancer) or setting specific (e.g., nursing home). Performance measures must assess if providers honor patient preference and coordinate care effectively. Additionally, if high-quality, patient-focused care is to be achieved, a performance measurement strategy should include both clinical quality measures and cross-cutting measures that assess care across settings and over time.

MAP found access to hospice and palliative care to be a key issue. Although enrollment in hospice continues to increase, the average length of stay is still relatively brief, with the majority of people utilizing the Medicare hospice benefit for less than six weeks. Additionally, while regional prevalence of hospice care programs is comparable, regional variation in utilization of hospice care persists.<sup>14</sup> These statistics signal a lack of awareness among patients about hospice care as an option. Clinician prognostication of end of life impacts referrals to hospice and the timing of referrals; however, MAP members noted that providing patients with information about hospice during the earlier stages of illness leads to a significant increase in the number of patients who elect hospice as a benefit. Integrating palliative services into care

upstream allows patients to become familiar with the approach and increases their awareness of the hospice benefit option. Population-level access and availability of care measures should assess if patients are provided appropriate and timely hospice and palliative care.

Another notable distinction of hospice and palliative care is that the family is consistently viewed as a critical component of the unit of care, because families are both caregivers and recipients of this care. Therefore, measurement of hospice and palliative care provides an opportunity to emphasize true person- and family-centered care. Additionally, a patient-centered performance measurement strategy must address the specific needs and preferences of an individual in care planning and goal setting. Hospice and palliative care are also team-based, requiring a group of providers, healthcare professionals, and caregivers (e.g., pharmacists, social workers, spiritual counselors) to coordinate patient care and family involvement.

Although hospice and palliative are distinct types of care, they have similar defining attributes, such as the emphasis on team-based care and holistic care that looks beyond treatment of physical symptoms. Accordingly, MAP identified 28 measurement opportunities that are important for hospice and palliative care. These opportunities address the need to provide access to affordable palliative and hospice services; the person- and family-centered nature of care, which focuses on individual goal setting and preferences; the team-based aspects of care coordination; and the holistic process of care that emphasizes not only the treatment of physical illness, but also emotional, mental, spiritual, social, and psychological well-being.

Recognizing the distinctions between hospice and palliative care and utilizing expert opinion, MAP prioritized the 28 high-leverage measurement opportunities. MAP prioritized seven for both hospice and palliative care, three specific to hospice care, and three specific to palliative care. The three opportunities specific to hospice care reflect patients' needs for increased access and communication, and the three opportunities specific to palliative care reflect patients' needs for education and care coordination. The measurement opportunities are not mutually exclusive, and some of the lower-prioritized opportunities may be encompassed within the higher-prioritized opportunities (e.g., care planning could encompass shared decision making).

## Highly Prioritized Measurement Opportunities for Both Hospice and Palliative Care

**Experience of care** is essential for assessing whether care was timely, coordinated, and met patient and family goals. As specifically applied to hospice, experience of care evaluation should incorporate unique aspects of hospice care, such as availability/access to the hospice care team and family/caregiver experience after patient death. The Family Evaluation of Hospice Care (FEHC) survey addresses the unique aspects of hospice care after patient death; however, MAP notes that the evaluation could be further enriched by assessing experience earlier in the care continuum and during transitions of care. For palliative care, the patient's and the family's experiences of care should be periodically assessed.

**Comprehensive assessment—including physical, psychological, spiritual, and social aspects of care—**should also incorporate ongoing reassessments. Comprehensive assessment can serve as a starting point for hospice care, facilitating care planning and assessment of patient/family preferences. It would also provide an opportunity to address emotional and spiritual aspects of care, given the difficulty in developing measures for these

areas. Within the context of palliative care, comprehensive assessment should be paired with care planning, advance directive discussions, and sharing medical records across providers to facilitate care coordination.

**Physical aspects of care—treating pain, dyspnea, constipation, and other symptoms using standardized scale—**should be periodically re-evaluated and incorporated into the care plan. Managing physical aspects of care is the logical initial focus for performance measurement because it has the strongest evidence base and helps avoid unwanted treatments and hospital/emergency department (ED) admissions and readmissions.

**Care Planning—establishing and periodically reviewing patient/family/caregiver goals—**should be done in conjunction with a comprehensive assessment. Care planning requires ongoing communication with patients, families, and other providers to ensure alignment of goals and care coordination. Within hospice, care planning should include a process for determining and reviewing preferences at regular intervals, as well as a plan for addressing each of the core areas of assessment. For palliative care programs, a focus should be on continually reassessing patient goals, because they may change as the illness progresses.

**Implementing patient/family/caregiver goals** occurs once the care plan has been established. It is imperative that a process is in place to respond to evolving goals.

**Avoiding unnecessary hospital and ED admissions** is an important indicator across the care continuum and a proxy for meeting patient needs and potentially reducing unwanted treatments.

**Psychological and psychiatric aspects of care—managing anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms—**is essential to compassionate care of the dying because behavioral changes significantly add to burden and can lead to hospital admissions

and crisis interventions. Commenters noted the importance of assessing access to psychological care for the family as well as the patient.

### Highly Prioritized Measurement Opportunities for Hospice Care

**Timeliness/responsiveness of care** is vital to providing optimal hospice care because it prevents unnecessary ED visits and hospital admissions and readmissions. Given that the average length of stay for hospice care is relatively brief, timely care is essential to support patients and caregivers, enhance autonomy, prevent unwanted admissions, and improve experience of care. Further, a time factor should be incorporated into other measurement opportunities, such as assessments and care planning. Commenters reinforced the need for processes that allow patients and families to communicate and escalate concerns with care; it is important that this process is clearly understood and accessible.

**Access to the healthcare team on a 24-hour basis** is important for hospice patients with complicated healthcare and comfort issues and their caregivers, because it emphasizes the importance of the team being available to assist when needed to reduce anxiety and quickly address patient and family needs. Timely intervention improves care coordination and limits unnecessary hospitalizations.

**Avoiding unwanted treatments**, when measured, serves as a proxy for appropriate levels of communication and determining if the care matches the patient's preferences. Unwanted treatments also include unnecessary hospital/ED admissions and readmissions.

### Highly Prioritized Measurement Opportunities for Palliative Care

**Sharing medical records (including advance directives) across all providers** is deemed important in palliative care to improve continuity of care and prevent unnecessary events such as hospitalization.

**Patient education and support** as part of palliative care leads to more effective self-/caregiver-management and may reduce the need for care interventions.

**Access to palliative care** addresses access across settings, beyond acute care. In addition, ensuring better access to palliative care helps to increase patients' awareness of hospice care as an option.

**Table 1 below notes the 28 measurement opportunities**, highlighting the 10 most highly prioritized opportunities for the Medicare hospice program and the 10 most highly prioritized opportunities for palliative care (indicated with check marks).

**TABLE 1. MEDICARE HOSPICE PROGRAM AND PALLIATIVE CARE MEASUREMENT OPPORTUNITIES**

| High-Leverage Measurement Opportunities   | Highly Prioritized Opportunity |                 |
|---|--------------------------------|-----------------|
|   | Medicare Hospice Program       | Palliative Care |
| <b>Access/Availability of Services</b>  |                                |                 |
| Access to hospice care across settings  |                                |                 |
| Access to palliative care across settings   |                                | ✓               |
| Access to the healthcare team on a 24-hour basis with a goal of providing timely and appropriate intervention | ✓                              |                 |
| Availability of spiritual care services   |                                |                 |
| Timeliness/responsiveness of care   | ✓                              |                 |

| High-Leverage Measurement Opportunities  | Highly Prioritized Opportunity |                 |
|--|--------------------------------|-----------------|
|  | Medicare Hospice Program       | Palliative Care |
| <b>Patient- and Family-Centered Care</b>   |                                |                 |
| Caregiver education and support  |                                |                 |
| Care of the imminently dying patient—assess that appropriate care is provided to patient as death nears  |                                |                 |
| Comprehensive assessment—including physical, psychological, spiritual, and social aspects of care  | ✓                              | ✓               |
| Culturally and linguistically appropriate care   |                                |                 |
| Experience of care—can encompass many domains of care including timeliness, meeting patient/family goals, and care coordination                        | ✓                              | ✓               |
| Patient education and support  |                                | ✓               |
| Psychological and psychiatric aspects of care—managing anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms | ✓                              | ✓               |
| Physical aspects of care—treating pain, dyspnea, constipation, and other symptoms using standardized scale   | ✓                              | ✓               |
| Spiritual, religious, and existential aspects of care—assessing concerns   |                                |                 |
| <b>Goals and Care Planning</b>   |                                |                 |
| Care planning—establishing and periodically reviewing patient/family/caregiver goals   | ✓                              | ✓               |
| Ethical and legal aspects of care—including advance directives and surrogate decision makers   |                                |                 |
| Implementing patient/family/caregiver goals  | ✓                              | ✓               |
| Grief and bereavement care planning  |                                |                 |
| Shared decision making—facilitates patient autonomy, control, and choice   |                                |                 |
| Social care planning—addressing social, practical, and legal needs of patient and caregivers   |                                |                 |
| <b>Care Coordination</b>   |                                |                 |
| Sharing medical records (including advance directives) across all providers  |                                | ✓               |
| Timely communication of patients’ goals across all providers   |                                |                 |
| <b>Provider Competency</b>   |                                |                 |
| Provider education   |                                |                 |
| Qualified healthcare teams   |                                |                 |
| <b>Appropriateness/Affordable Care</b>   |                                |                 |
| Appropriate level of services  |                                |                 |
| Avoiding unnecessary hospital and ED admissions  | ✓                              | ✓               |
| Avoiding unwanted treatments   | ✓                              |                 |
| Cost of care   |                                |                 |

## Public Comments

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Commenters affirmed these high-leverage measurement opportunities; however, several commenters suggested different rankings of the most highly prioritized opportunities. For example, several commenters requested that structural measures around provider competency and qualified healthcare teams be considered a highly

prioritized measurement opportunity, noting the lack of certification for palliative care programs. Commenters also suggested revisiting the prioritization of the measurement opportunities with a deeper consideration of current performance, opportunity for improvement, and impact. In future efforts, MAP aims to incorporate elements of this data-driven approach into its deliberations.

## APPLYING AND REFINING EXISTING MEASURES

To begin to address the high-leverage measurement opportunities, MAP identified NQF-endorsed<sup>®</sup> measures that could potentially assess hospice and palliative care across settings, and identified measures in the pipeline that could potentially fill measure gaps. Additional testing and development of the Assessing Care of Vulnerable Elders (ACOVE) indicators represent an opportunity to fill measure gaps. For example, the end-of-life ACOVE indicators have not previously been applied to performance measurement because of limitations in identifying end-of-life patients through claims data; however, these indicators may be more easily specified for the Medicare Hospice Quality Measurement Program because the program's entire population is considered to be at the end of life.

In identifying measures for hospice and palliative care, MAP noted the possibility of undesirable consequences from applying certain measures. For example, measures of hospital mortality could lead to patients being transferred to hospice shortly before death to decrease mortality rates. Measures assessing weight loss for patients in long-term care facilities could lead to inappropriate provision of tube feeding for palliative patients and an increase in transfers to hospitals. Instead, performance measures should assess adherence to patient preferences and timely transfer to hospice care.

Performance measurement for hospice and palliative care should include both clinical quality

measures and patient-focused cross-cutting measures. Public comment strongly supported outcome-based measures that assess patient care across settings and time. MAP recognizes that the field of hospice care quality measurement is still new and lacks evidence in critical areas (e.g., goals of care, spiritual counseling). Evidence is most prominent in physical symptom management (e.g., pain, dyspnea), creating a small pool of existing measures. Accordingly, MAP, with support from public commenters, suggests a phased approach to measurement of hospice and palliative care, beginning with the existing measures, many of which are clinically focused, and phasing in cross-cutting measures over time. As reflected in public comments, this approach would help minimize provider burden. Some existing measures should be explored for application to broader settings and populations. For example, some existing cancer care measures should be specified and tested for broader application. MAP also recognizes that certain areas of holistic, team-based care (e.g., spiritual counseling, shared decision making) lack sufficient evidence.<sup>15</sup> In these areas, MAP suggests using structural and process measures while research and evidence continues to build. As performance measurement for hospice and palliative care is relatively new, MAP recognizes a unique opportunity to build truly patient-centered measurement from the start. Creating feedback loops will inform building the evidence base and refining measures.

**Table 2 below highlights NQF-endorsed measures that address the high-leverage measurement opportunities.** The measures are marked with an “X” if they are ready for immediate application in the Medicare Hospice Quality Measurement Program or a particular palliative care setting. For the Medicare hospice program, one measure is already in use in the program and is marked as “Finalized,” and six additional measures were recommended by MAP in its pre-rulemaking report and are marked as “MAP supported in pre-rulemaking.”

A measure is ready for immediate application if it is endorsed by NQF for use in that setting. MAP encourages additional development and testing of these measures to ensure their applicability across multiple hospice and palliative care settings. MAP has also identified potential opportunities to refine measures to more closely address priorities for hospice and palliative care. These refinements, which would require additional development and testing, are noted in the “Additional Considerations” column. Suggested refinements include expanding measures to address multiple conditions or bundling measures to create composites.

**TABLE 2. MEASURES FOR APPLICATION OR REFINEMENT IN HOSPICE AND PALLIATIVE CARE**

| High-Leverage Measurement Opportunities/ Measures  | Medicare Hospice Program | Palliative Care |                          |                               |      | Additional Considerations   |
|--|--------------------------|-----------------|--------------------------|-------------------------------|------|---|
|  |                          | Hospital        | Clinician Office Setting | PAC/LTC Settings (facilities) | Home |   |
| Access to palliative care  |                          |                 |                          |                               |      | No available NQF-endorsed measures  |
| Access to hospice care   |                          |                 |                          |                               |      |   |
| <b>0216 Proportion admitted to hospice for less than 3 days</b>  | X                        |                 |                          |                               |      | Explore expanding beyond cancer population  |
| Access to the healthcare team on a 24-hour basis   |                          |                 |                          |                               |      | No available NQF-endorsed measures  |
| Timeliness/responsiveness of care  |                          |                 |                          |                               |      | No available NQF-endorsed measures  |
| Availability of spiritual care services  |                          |                 |                          |                               |      | No available NQF-endorsed measures  |
| Comprehensive assessment—including physical, psychological, spiritual, and social aspects of care  |                          |                 |                          |                               |      | No available NQF-endorsed measures  |
| Psychological and psychiatric aspects of care—managing anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms |                          |                 |                          |                               |      |   |
| <b>0518 Depression assessment conducted</b>  |                          |                 |                          |                               | X    | Explore application to hospice and palliative care patient populations;<br>Commenters noted that depression measures should also include a plan for follow-up |

| High-Leverage Measurement Opportunities/ Measures   | Medicare Hospice Program        | Palliative Care |                          |                               |      | Additional Considerations   |
|---|---------------------------------|-----------------|--------------------------|-------------------------------|------|---|
|   |                                 | Hospital        | Clinician Office Setting | PAC/LTC Settings (facilities) | Home |   |
| <b>Spiritual, religious, and existential aspects of care—assessing concerns</b>   |                                 |                 |                          |                               |      |   |
| 1647 Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss | X                               |                 |                          |                               |      |   |
| <b>Physical aspects of care—treating pain, dyspnea, constipation, and other symptoms using standardized scale</b>   |                                 |                 |                          |                               |      |   |
| 0209 Comfortable dying—pain brought to a comfortable level within 48 hours of initial assessment  | Finalized                       |                 |                          |                               |      |   |
| 1634 Hospice and palliative care—pain screening (paired with 1637)  | MAP supported in pre-rulemaking |                 |                          |                               |      | Reassessment measures are also needed                                     |
| 1637 Hospice and palliative care—pain assessment (paired with 1634)   | MAP supported in pre-rulemaking |                 |                          |                               |      |   |
| 1638 Hospice and palliative care—dyspnea treatment (paired with 1639)   | MAP supported in pre-rulemaking |                 |                          |                               |      |   |
| 1639 Hospice and palliative care—dyspnea screening (paired with 1638)   | MAP supported in pre-rulemaking |                 |                          |                               |      | Reassessment measures are also needed                                     |
| 1617 Patients treated with an opioid who are given a bowel regimen  | MAP supported in pre-rulemaking |                 |                          |                               |      |   |
| 0179 Improvement in dyspnea   |                                 |                 |                          |                               | X    | Explore application to hospice and palliative care patient populations    |
| 0384 Oncology: pain intensity quantified—medical oncology and radiation oncology (paired with 0383)   |                                 |                 | X                        |                               |      | Explore expanding to all cancer patients and beyond the cancer population |
| <b>Care of the imminently dying patient</b>   |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Culturally and linguistically appropriate care</b>   |                                 |                 |                          |                               |      |   |
| Under review; not yet NQF-endorsed Cross-cultural communication domain of the Communication Climate Assessment Toolkit  |                                 |                 | X                        |                               |      |   |
| Under review; not yet NQF-endorsed Health literacy domain of Communication Climate Assessment Toolkit   |                                 |                 | X                        |                               |      |   |
| <b>Patient education and support</b>  |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Caregiver education and support</b>  |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |



| High-Leverage Measurement Opportunities/ Measures  | Medicare Hospice Program        | Palliative Care |                          |                               |      | Additional Considerations   |
|--|---------------------------------|-----------------|--------------------------|-------------------------------|------|---|
|  |                                 | Hospital        | Clinician Office Setting | PAC/LTC Settings (facilities) | Home |   |
| <b>Experience of care</b>  |                                 |                 |                          |                               |      |   |
| <b>0208 Family Evaluation of Hospice Care</b>  | MAP supported in pre-rulemaking |                 |                          |                               |      | Explore development of an aligned measure for palliative care that also incorporates patient evaluation of care |
| <b>1623 Bereaved Family Survey</b>   | X                               |                 |                          | X                             |      | <i>Note:</i> Measure developed for VA healthcare system   |
| <b>1632 CARE—Consumer Assessments and Reports of End of Life</b>   | X                               | X               |                          | X                             | X    |   |
| <b>Care planning—establishing and periodically reviewing patient/family/caregiver goals</b>                              |                                 |                 |                          |                               |      |   |
| <b>0383 Oncology: plan of care for pain—medical oncology and radiation oncology (paired with 0384)</b>                   |                                 |                 | X                        |                               |      | Explore expanding to all cancer patients and beyond the cancer population                                       |
| <b>1626 Patients admitted to ICU who have care preferences documented</b>  |                                 | X               |                          |                               |      |   |
| <b>1641 Hospice and palliative care—treatment preferences</b>  | X                               |                 |                          |                               |      |   |
| <b>Implementing patient/family/caregiver goals</b>   |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Shared decision making</b>  |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Grief and bereavement care planning</b>   |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Social care planning—addressing social, practical, and legal needs of patient and caregivers</b>                      |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Ethical and legal aspects of care—including advance directives and surrogate decision makers</b>                      |                                 |                 |                          |                               |      |   |
| <b>0326 Advance care plan</b>  | X                               | X               | X                        | X                             | X    | Explore expanding beyond older adults   |
| <b>Timely communication of patients' goals across all providers</b>  |                                 |                 |                          |                               |      |   |
| <b>0097 Medication reconciliation</b>  |                                 |                 | X                        |                               |      | Explore expanding beyond older adults   |
| <b>0648 Timely transition of transmission record (inpatient discharges to home/self-care, or any other site of care)</b> |                                 | X               |                          |                               |      |   |
| <b>Sharing medical records (including advance directives) across all providers</b>                                       |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Provider education</b>  |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |
| <b>Qualified healthcare teams</b>  |                                 |                 |                          |                               |      | No available NQF-endorsed measures  |

| High-Leverage Measurement Opportunities/ Measures  | Medicare Hospice Program | Palliative Care |                          |                               |      | Additional Considerations   |
|--|--------------------------|-----------------|--------------------------|-------------------------------|------|---|
|  |                          | Hospital        | Clinician Office Setting | PAC/LTC Settings (facilities) | Home |   |
| <b>Appropriate level of services</b>   |                          |                 |                          |                               |      |   |
| <b>O213 (under review) Proportion admitted to the ICU in the last 30 days of life</b>                  | X                        |                 |                          |                               |      | Explore expanding beyond cancer population  |
| <b>O214 (under review) Proportion dying from cancer in an acute care setting</b>                       | X                        |                 |                          |                               |      | Explore expanding beyond cancer population  |
| <b>Avoiding unwanted treatments</b>  |                          |                 |                          |                               |      |   |
| <b>O210 (under review) Proportion receiving chemotherapy in the last 14 days of life</b>               | X                        |                 |                          |                               |      | Explore expanding beyond cancer population<br>Although commenters support use of this measure, there needs to be consideration for the unintended consequence of reducing access to palliative chemotherapy |
| <b>1625 Hospitalized patients who die an expected death with an ICD that has been deactivated</b>      |                          | X               |                          |                               |      |   |
| <b>Avoiding hospital and ED admissions</b>   |                          |                 |                          |                               |      |   |
| <b>O211 (under review) Proportion with more than one emergency room visit in the last days of life</b> | X                        |                 |                          |                               |      | Explore expanding beyond cancer population  |
| <b>O212 (under review) Proportion with more than one hospitalization in the last 30 days of life</b>   | X                        |                 |                          |                               |      | Explore expanding beyond cancer population  |
| <b>O171 Acute care hospitalization (risk-adjusted)</b>   |                          |                 |                          |                               | X    |   |
| <b>O173 Emergency department use without hospitalization</b>   |                          |                 |                          |                               | X    |   |
| <b>Cost of care</b>  |                          |                 |                          |                               |      | No available NQF-endorsed measures  |

MAP was unable to identify available measures for several of the highly prioritized measurement opportunities (noted in Table 2 as “No available NQF-endorsed measures”); of these measure gaps, MAP identified the following to be of highest priority:

- Access to hospice and palliative care
- Access to the healthcare team on a 24-hour basis
- Comprehensive assessment (bundled measure)
- Patient education and support
- Timeliness/responsiveness of care

- Psychological and psychiatric aspects of care, particularly anxiety and agitation

To achieve a comprehensive core set of hospice and palliative care measures, MAP encourages the following phasing strategy:

1. Immediate application of available measures
2. Further refinement of measures that can be expanded to cross populations and settings
3. Testing and development to fill the highest-priority measure gaps with a focus on outcomes

## Public Comments

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Commenters strongly reinforced MAP's view that this is a unique opportunity to build a patient-centered measurement approach. Commenters signaled a need for the testing and development of cross-cutting measures in order to address the high-leverage measurement opportunities recommended in this report. They also emphasized the importance of patient-reported measures for hospice and palliative care. Additionally, commenters emphasized that consistency in measurement across settings is

essential to the ability to compare patient and family experiences and quality of life. Finally, commenters recommended that consumers should be involved early in the measure development process to ensure that measures are meaningful and useful to consumers. Involving the patient community in all steps of the measure development and selection process will ensure a patient-centric approach. Accordingly, MAP membership and the steering committees involved in NQF's endorsement process include consumer representatives.

# PATHWAY FOR IMPROVING MEASURE APPLICATION FOR HOSPICE AND PALLIATIVE CARE

Hospice and palliative care provide the opportunity to emphasize two significant NQS priorities: person- and family-centered care, and care coordination. A holistic approach to the entire well-being of the patient—physical, mental, social, emotional, psychological, and spiritual—and including family and the caregiver team in the care process, represents a shift in how care has typically been delivered. Commenters reinforced the need for measures that assess this holistic approach to care. MAP recognizes that a performance measurement strategy for hospice care provides a unique opportunity to pave the way for positive changes for all aspects of healthcare, leading to a better coordinated, team-based approach that emphasizes patients' values and preferences.

This performance measurement coordination strategy identifies key measurement opportunities and available measures for hospice and palliative care. Many of these concepts align with the measurement priorities and high-leverage measurement opportunities identified in the *MAP Post-Acute Care and Long-Term Care Coordination Strategy*, the *MAP Dual Eligible Beneficiaries Interim and Final Reports*, the *MAP Cancer Hospitals Coordination Strategy*, and the NQF-endorsed *Multiple Chronic Conditions Measurement Framework* (Appendix D highlights the alignment of the measurement priorities identified by all of these efforts). All of these reports emphasize the need for patient-centered, cross-cutting measures that enable measurement across the episode of care, in addition to specific, clinically focused measures. This can be facilitated by standardized data collection and reporting mechanisms that encourage documenting and

sharing patient preferences across settings; filling measure gaps through development, testing, and endorsement; and establishing feedback loops.

## Common Data Collection and Transmission Platform

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The need for a common data collection and transmission platform and electronic exchange of information is particularly pertinent, since hospice and palliative care often occurs across multiple settings and involves care transitions. Commenters reinforced this point, noting that a critical barrier to measuring the palliative care of patients is the lack of a consistent method to identify them (i.e., V-codes are not consistently reported). Commenters supported MAP's previously delineated data principles, which would reduce quality measurement burden and facilitate health information technology adoption and use:

- A standardized mechanism is needed for measurement data collection and transmission.
- A library of all data elements needed for all measures should be created and maintained.
- The data collection and transmission platform should support patient-centered measurement by enabling the collection of patient-reported data.
- Data collection should occur during the course of care.
- Data collection should enable analysis at multiple levels.
- Systematic review of data and feedback loops should be implemented.
- Timely feedback of measurement results is imperative.

As an initial step, MAP suggests creating standardized data elements to support measure development, allowing for analysis and coordination across the continuum of care. For example, standardized data elements for collecting patient preferences and care plans would allow for consistent documentation across settings. This information could then be more readily accessed for use in measures. Similarly, the [MAP safety coordination strategy](#) notes the need for uniform discharge plan elements that incorporate best practices for care transitions.

## Addressing Measure Gaps

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Significant measure gaps will need to be addressed to provide a comprehensive picture of quality for hospice and palliative care. MAP has identified potential pathways for filling some of these gaps through development, testing, endorsement, and implementation. Most importantly, an aligned set of quality measures for hospice and palliative care should represent the cross-setting nature of this type of care, across diseases and settings. MAP recommends creating a family of measures that can be applied across programs, settings, levels of analysis, and populations to ensure a patient-focused, cross-cutting assessment of quality. For example, implementing aligned measures that assess care transitions in each setting and across levels of analysis would help to identify where care transitions can improve. Commenters noted the need for funding to address the measure gaps and supported MAP's efforts to encourage the development of measures to fill those gaps. When identifying families of measures, MAP intends to define pathways for filling gaps that include outreach to measure developers and measure development funders.

As de novo measure development and modification of existing measures for broader application occur in these areas, feedback loops must be incorporated to bolster the evidence base and to monitor undesirable consequences of measurement. Although the challenge for hospice and palliative care measurement is great, the opportunity is equally so—to move healthcare toward a truly person- and family-centered, coordinated model of care.

## ENDNOTES

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## APPENDIX A: MAP Background

### Purpose

The Measure Applications Partnership (MAP) is a public-private partnership convened by the National Quality Forum (NQF) for providing input to the Department of Health and Human Services (HHS) on selecting performance measures for public reporting, performance-based payment programs, and other purposes. The statutory authority for MAP is the Affordable Care Act (ACA), which requires HHS to contract with NQF (as the consensus-based entity) to “convene multi-stakeholder groups to provide input on the selection of quality measures” for various uses.<sup>1</sup>

MAP’s careful balance of interests—across consumers, businesses and purchasers, labor, health plans, clinicians, providers, communities and states, and suppliers—ensures HHS will receive varied and thoughtful input on performance measure selection. In particular, the ACA-mandated annual publication of measures under consideration for future federal rulemaking allows MAP to evaluate and provide upstream input to HHS in a more global and strategic way.

MAP is designed to facilitate alignment of public- and private-sector uses of performance measures to further the National Quality Strategy’s (NQS’s) three-part aim of creating better, more affordable care, and healthier people.<sup>2</sup> Anticipated outcomes from MAP’s work include:

- A more cohesive system of care delivery;
- Better and more information for consumer decision making;
- Heightened accountability for clinicians and providers;
- Higher value for spending by aligning payment with performance;
- Reduced data collection and reporting burden through harmonizing measurement activities

across public and private sectors; and

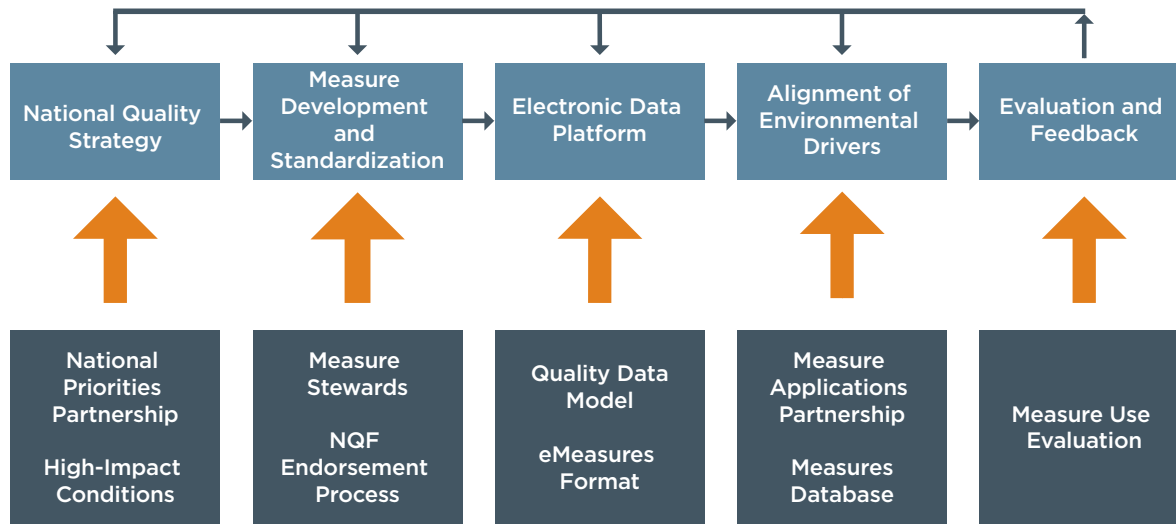
- Improvement in the consistent provision of evidence-based care.

### Coordination with Other Quality Efforts

MAP activities are designed to coordinate with and reinforce other efforts for improving health outcomes and healthcare quality. Key strategies for reforming healthcare delivery and financing include publicly reporting performance results for transparency, aligning payment with value, rewarding providers and professionals for using health information technology (health IT) to improve patient care, and providing knowledge and tools to healthcare providers and professionals to help them improve performance. Many public- and private-sector organizations have important responsibilities in implementing these strategies, including federal and state agencies, private purchasers, measure developers, groups convened by NQF, accreditation and certification entities, various quality alliances at the national and community levels, as well as the professionals and providers of healthcare.

Foundational to the success of all of these efforts is a robust “quality measurement enterprise” (Figure A-1) that includes:

- Setting priorities and goals for improvement;
- Standardizing performance measures;
- Constructing a common data platform that supports measurement and improvement;
- Applying measures to public reporting, performance-based payment, health IT meaningful use programs, and other areas; and
- Promoting performance improvement in all healthcare settings.

**FIGURE A-1. FUNCTIONS OF THE QUALITY MEASUREMENT ENTERPRISE**

The National Priorities Partnership (NPP) is a multi-stakeholder group convened by NQF to provide input to HHS on the NQS, by identifying priorities, goals, and global measures of progress.<sup>3</sup> Another NQF-convened group, the Measure Prioritization Advisory Committee, has defined high-impact conditions for the Medicare and child health populations.<sup>4</sup> Cross-cutting priorities and high-impact conditions provide the foundation for all of the subsequent work within the quality measurement enterprise.

Measure development and standardization of measures are necessary to assess the baseline relative to the NQS priorities and goals, determine the current state and opportunities for improvement, and monitor progress. The NQF endorsement process meets certain statutory requirements for setting consensus standards and also provides the resources and expertise necessary to accomplish the task. A platform of data sources, with increasing emphasis on electronic collection and transmission, provides the data needed to calculate measures for use in accountability programs and to provide immediate feedback and clinical decision support to providers for performance improvement.

Alignment around environmental drivers, such as public reporting and performance-based

payment, is MAP's role in the quality measurement enterprise. By considering and recommending measures for use in specific applications, MAP will facilitate the alignment of public- and private-sector programs and harmonization of measurement efforts under the NQS.

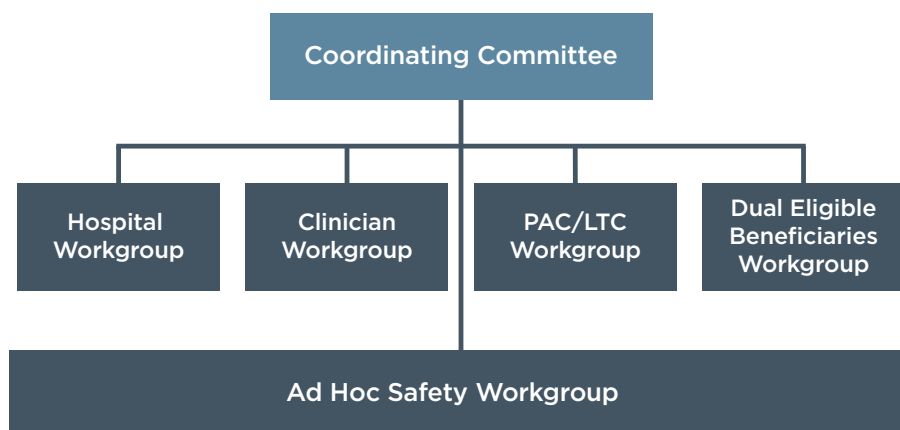
Finally, evaluation and feedback loops for each of the functions of the quality measurement enterprise ensure that each of the various activities is driving desired improvements.<sup>5,6</sup> Further, the evaluation function monitors for potential unintended consequences that may result.

## Function

Composed of a two-tiered structure, MAP's overall strategy is set by the Coordinating Committee, which provides final input to HHS. Working directly under the Coordinating Committee are five advisory workgroups responsible for advising the Committee on using measures to encourage performance improvement in specific care settings, providers, and patient populations (Figure A-2). More than 60 organizations representing major stakeholder groups, 40 individual experts, and 9 federal agencies (*ex officio* members) are represented on the Coordinating Committee and workgroups.



FIGURE A-2. MAP STRUCTURE



The NQF Board of Directors oversees MAP. The Board will review any procedural questions and periodically evaluate MAP's structure, function, and effectiveness, but will not review the Coordinating Committee's input to HHS. The Board selected the Coordinating Committee and workgroups based on Board-adopted selection criteria. Balance among stakeholder groups was paramount. Because MAP's tasks are so complex, including individual subject matter experts in the groups also was imperative.

All MAP activities are conducted in an open and transparent manner. The appointment process included open nominations and a public comment period. MAP meetings are broadcast, materials and summaries are posted on the NQF website, and public comments are solicited on recommendations.

MAP decision making is based on a foundation of established guiding frameworks. The NQS is the primary basis for the overall MAP strategy. Additional frameworks include the high-impact conditions determined by the NQF-convened Measure Prioritization Advisory Committee, the NQF-endorsed<sup>®</sup> Patient-Focused Episodes of Care framework,<sup>7</sup> the HHS Partnership for Patients safety initiative,<sup>8</sup> the HHS Prevention and Health Promotion Strategy,<sup>9</sup> the HHS Disparities Strategy,<sup>10</sup> and the HHS Multiple Chronic Conditions

framework.<sup>11</sup> Additionally, the MAP Coordinating Committee has developed measure selection criteria to help guide MAP decision making.

One of MAP's early activities was the development of measure selection criteria. The selection criteria are intended to build on, not duplicate, the NQF endorsement criteria. The measure selection criteria characterize the fitness of a measure set for use in a specific program by, among other things, how closely they align with the NQS's priority areas and address the high-impact conditions, and by the extent to which the measure set advances the purpose of the specific program without creating undesirable consequences.

## Timeline and Deliverables

MAP's initial work included performance measurement coordination strategies and pre-rulemaking input on the selection of measures for public reporting and performance-based payment programs. Each of the coordination strategies addresses:

- Measures and measurement issues, including measure gaps;
- Data sources and health IT implications, including the need for a common data platform;
- Alignment across settings and across public- and private-sector programs;

- Special considerations for dual eligible beneficiaries; and
- Path forward for improving measure applications.

On October 1, 2011, MAP issued three coordination strategy reports. The report on coordinating readmissions and healthcare-acquired conditions focuses on alignment of measurement, data collection, and other efforts to address these safety issues across public and private payers.<sup>12</sup> The report on coordinating clinician performance measurement identifies the characteristics of an ideal measure set for assessing clinician performance, advances measure selection criteria as a tool, and provides input on a recommended measure set and priority gaps for clinician public reporting and performance-based payment programs.<sup>13</sup> An interim report on performance measurement for dual eligible beneficiaries offers a strategic approach that includes a vision, guiding principles, characteristics of high-need subgroups, and high-leverage opportunities for improvement, all of which informed the content of this final report.<sup>14</sup>

On February 1, 2012, MAP submitted the *Pre-Rulemaking Final Report* and the *Coordination Strategy for Post-Acute Care and Long-Term Care Performance Measurement Report*. The *Pre-Rulemaking Final Report* provided input on more than 350 performance measures under consideration for use in nearly 20 federal healthcare programs.<sup>15</sup> The report is part of MAP's annual analysis of measures under consideration for use in federal public reporting and performance-based payment programs, in addition to efforts for alignment of measures with those in the private sector. The *Coordination Strategy for Post-Acute Care and Long-Term Care Performance Measurement* report made recommendations on aligning measurement, promoting common goals for PAC and LTC providers, filling priority measure gaps, and standardizing care planning tools.<sup>16</sup>

Additional coordination strategies for dual eligible beneficiary care and cancer care will be released in June 2012, concurrent with this report.

## Endnotes

- 1 U.S. Government Printing Office (GPO). *Patient Protection and Affordable Care Act (ACA), PL 111-148 Sec. 3014*. Washington, DC: GPO; 2010, p.260. Available at [www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf](http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf). Last accessed August 2011.
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**11** HHS, *HHS Initiative on Multiple Chronic Conditions*, Washington, DC: HHS; 2011. Available at [www.hhs.gov/ash/initiatives/mcc/](http://www.hhs.gov/ash/initiatives/mcc/). Last accessed March 2012.

**12** NQF, *Coordination Strategy for Healthcare-Acquired Conditions and Readmissions Across Public and Private Payers*. Washington, DC: NQF; 2011. Available at [www.qualityforum.org/map/](http://www.qualityforum.org/map/). Last accessed March 2012.

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## APPENDIX B: Roster for the MAP Post-Acute Care/Long-Term Care Workgroup

| CHAIR (VOTING)  |   |
|---|---|
| Carol Raphael, MPA  |   |
| ORGANIZATIONAL MEMBERS (VOTING)                               | REPRESENTATIVE                                    |
| Aetna   | Randall Krakauer, MD                              |
| American Medical Rehabilitation Providers Association         | Suzanne Snyder, PT                                |
| American Physical Therapy Association                         | Roger Herr, PT, MPA, COS-C                        |
| Family Caregiver Alliance                                     | Kathleen Kelly, MPA                               |
| HealthInsight   | Juliana Preston, MPA                              |
| Kindred Healthcare  | Sean Muldoon, MD                                  |
| National Consumer Voice for Quality Long-Term Care            | Lisa Tripp, JD                                    |
| National Hospice and Palliative Care Organization             | Carol Spence, PhD                                 |
| National Transitions of Care Coalition                        | James Lett II, MD, CMD                            |
| Providence Health and Services                                | Robert Hellrigel                                  |
| Service Employees International Union                         | Charissa Raynor                                   |
| Visiting Nurses Association of America                        | Margaret Terry, PhD, RN                           |
| EXPERTISE   | INDIVIDUAL SUBJECT MATTER EXPERT MEMBERS (VOTING) |
| Clinician/Nursing   | Charlene Harrington, PhD, RN, FAAN                |
| Care Coordination   | Gerri Lamb, PhD                                   |
| Clinician/Geriatrics  | Bruce Leff, MD                                    |
| State Medicaid  | MaryAnne Lindeblad, MPH                           |
| Measure Methodologist   | Debra Saliba, MD, MPH                             |
| Health IT   | Thomas von Sternberg, MD                          |
| FEDERAL GOVERNMENT MEMBERS (NON-VOTING, EX OFFICIO)           |   |
| Agency for Healthcare Research and Quality (AHRQ)             | Judy Sangl, ScD                                   |
| Centers for Medicare & Medicaid Services (CMS)                | Shari Ling  |
| Veterans Health Administration                                | Scott Shreve, MD                                  |
| MAP COORDINATING COMMITTEE CO-CHAIRS (NON-VOTING, EX OFFICIO) |   |
| George Isham, MD, MS  |   |
| Elizabeth McGlynn, PhD, MPP                                   |   |

## APPENDIX C: Roster for the MAP Coordinating Committee

| CHAIR (VOTING)                              |   |
|---|---|
| George Isham, MD, MS                        |   |
| Elizabeth McGlynn, PhD, MPP                 |   |
| ORGANIZATIONAL MEMBERS (VOTING)             | REPRESENTATIVES                                   |
| AARP  | Joyce Dubow, MUP                                  |
| Academy of Managed Care Pharmacy            | Marissa Schlaifer, RPh, MS                        |
| AdvaMed                                     | Steven Brotman, MD, JD                            |
| AFL-CIO                                     | Gerald Shea                                       |
| America's Health Insurance Plans            | Aparna Higgins, MA                                |
| American College of Physicians              | David Baker, MD, MPH, FACP                        |
| American College of Surgeons                | Frank Opelka, MD, FACS                            |
| American Hospital Association               | Rhonda Anderson, RN, DNSc, FAAN                   |
| American Medical Association                | Carl Sirio, MD                                    |
| American Medical Group Association          | Sam Lin, MD, PhD, MBA                             |
| American Nurses Association                 | Marla Weston, PhD, RN                             |
| Catalyst for Payment Reform                 | Suzanne Delbanco, PhD                             |
| Consumers Union                             | Doris Peter, PhD                                  |
| Federation of American Hospitals            | Chip N. Kahn                                      |
| LeadingAge (formerly AAHSA)                 | Cheryl Phillips, MD, AGSF                         |
| Maine Health Management Coalition           | Elizabeth Mitchell                                |
| National Association of Medicaid Directors  | Foster Gesten, MD                                 |
| National Partnership for Women and Families | Christine Bechtel, MA                             |
| Pacific Business Group on Health            | William Kramer, MBA                               |
| EXPERTISE                                   | INDIVIDUAL SUBJECT MATTER EXPERT MEMBERS (VOTING) |
| Child Health                                | Richard Antonelli, MD, MS                         |
| Population Health                           | Bobbie Berkowitz, PhD, RN, CNAA, FAAN             |
| Disparities                                 | Joseph Betancourt, MD, MPH                        |
| Rural Health                                | Ira Moscovice, PhD                                |
| Mental Health                               | Harold Pincus, MD                                 |
| Post-Acute Care/ Home Health/ Hospice       | Carol Raphael, MPA                                |

| FEDERAL GOVERNMENT MEMBERS<br>(NON-VOTING, EX OFFICIO) | REPRESENTATIVES                  |
|--|----------------------------------|
| Agency for Healthcare Research and Quality             | Nancy Wilson, MD, MPH            |
| Centers for Disease Control and Prevention             | Chesley Richards, MD, MPH        |
| Centers for Medicare & Medicaid Services               | Patrick Conway, MD MSc           |
| Health Resources and Services Administration           | Ahmed Calvo, MD, MPH             |
| Office of Personnel Management/FEHBP                   | John O'Brien                     |
| Office of the National Coordinator for HIT             | Kevin Larsen, MD                 |
| ACCREDITATION/CERTIFICATION LIAISONS<br>(NON-VOTING)   | REPRESENTATIVES                  |
| American Board of Medical Specialties                  | Christine Cassel, MD             |
| National Committee for Quality Assurance               | Peggy O'Kane, MPH                |
| The Joint Commission                                   | Mark Chassin, MD, FACP, MPP, MPH |

## APPENDIX D: Hospice and Palliative Care Measure Priority Alignment

The table below highlights the alignment of hospice and palliative care measure concepts with the measure concepts identified by the [MAP Post-Acute Care and Long-Term Care Coordination Strategy](#), the [MAP Dual Eligible](#)

[Beneficiaries Interim and Final Reports](#), the [MAP Cancer Hospitals Coordination Strategy](#), and the NQF-endorsed [Multiple Chronic Conditions Measurement Framework](#).

| Hospice and Palliative Care Measurement Priority | MAP PAC-LTC Measurement Priorities | MAP Dual-Eligible Beneficiaries High-Leverage Opportunities | MAP Cancer Hospitals Measurement Priorities | NQF-endorsed MCC Measurement Framework Concepts |
|--|------------------------------------|---|---|---|
| Access/Availability of Services                  | ✓                                  | ✓   |   | ✓   |
| Patient and Family Centered Care                 | ✓                                  | ✓   | ✓   | ✓   |
| Goal and Care Planning                           | ✓                                  | ✓   | ✓   | ✓   |
| Care Coordination                                | ✓                                  | ✓   | ✓   | ✓   |
| Provider Competency                              |                                    |   |   |   |
| Appropriateness/Affordable Care                  | ✓                                  |   | ✓   | ✓   |

## APPENDIX E: Public Comments on Draft Report

| Comment Category                      | Commenter Organization                              | Commenter Name | Comment  |
|---------------------------------------|---|----------------|--|
| <b>General Comments on the Report</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>NCHPC commends the committee on this report. We heartily endorse the direction indicated, specifically the calls for:</p> <ul style="list-style-type: none"> <li>-“both clinical quality measures and cross-cutting measures that assess care across settings and over time.”</li> <li>-“performance measures should assess adherence to patient preferences and timely transfer to hospice care”</li> <li>-“As performance measurement for hospice and palliative care is relatively new, MAP recognizes a unique opportunity to build truly patient-centered measurement from the start.”</li> </ul> <p>We note one error: the statement “patients in nursing homes often need to obtain an individual waiver in order to elect hospice care” is misleading.</p> <p>Finally, we note that the current NQF endorsement process has made it very hard to develop a cohesive, comprehensive and coherent set of measures that cross settings and disease types. For instance, pain measures endorsed for cancer cannot be endorsed for use in other patient populations. Given the very limited resources for measure development and testing, the field will never have enough money to test every single measure in every single setting within every single disease category. A feasible, scientifically valid approach to surmounting this problem is needed.’</p> |
| <b>General Comments on the Report</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>AAHPM commends the committee on this report. We heartily endorse the direction indicated, specifically the calls for: “both clinical quality measures and cross-cutting measures that assess care across settings and over time”, “performance measures should assess adherence to patient preferences and timely transfer to hospice care” and “as performance measurement for hospice and palliative care is relatively new, MAP recognizes a unique opportunity to build truly patient-centered measurement from the start.”</p> <p>This report will help all involved to implement more systematic quality measurement, improvement and reporting in hospice and palliative care. We particularly hope that other MAP groups looking at measurement strategies for other populations and settings will note the need to implement cross-cutting measures, and will heed the call to integrate patient-centered measures about the palliative domains of care into their measurement strategies.’</p>  |
| <b>General Comments on the Report</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>We believe the statement “patients in nursing homes often need to obtain an individual waiver in order to elect hospice care” to be inaccurate.</p> <p>The need for a common data collection and transmission platform and electronic exchange of information may be particularly pertinent in hospice and palliative care, but we need further study of its utility in this field. Such systems can be very costly to implement and not all important aspects of the patient experience can be distilled into discrete quantifiable data elements.’</p>  |



| Comment Category                      | Commenter Organization                | Commenter Name | Comment   |
|---------------------------------------|---------------------------------------|----------------|---|
| <b>General Comments on the Report</b> | American Cancer Society               | Rebecca Kirch  | <p>'The American Cancer Society commends the committee for its comprehensive work on this report and inclusion of the listed measure concepts as a strong start for further measure enhancement and development to come. Palliative care delivers expert attention to physical and psychological symptoms and improved communication and coordination. In particular, we urge development of future measures addressing assessment AND management of pain, symptoms and distress, including a suite of measures for psychosocial and spiritual aspects of care, that expands across multiple care settings and extends across disease types (beyond cancer). This expansion effort will be essential to deliver patient-centered and family focused care for growing numbers of people facing serious illness and multiple chronic conditions to ensure we preserve and promote their quality of life alongside disease-directed treatment.'</p>  |
| <b>General Comments on the Report</b> | American Nurses Association           | Maureen Dailey | <p>The ANA applauds the leadership of Carol Raphael, the chair, and the work of the MAP Workgroup on this thoughtful and comprehensive report. ANA support the NCHPC comments, including the commendations on these specific measurement principles:</p> <p>"Both clinical quality measures and cross-cutting measures that assess care across settings and over time."</p> <p>"performance measures should assess adherence to patient preferences and timely transfer to hospice care"</p> <p>"As performance measurement for hospice and palliative care is relatively new, MAP recognizes a unique opportunity to build truly patient-centered measurement from the start."</p>   |
| <b>General Comments on the Report</b> | American Physical Therapy Association | Heather Smith  | <p>The American Physical Therapy Association (APTA) believes that the Post-Acute and Long-Term Care Draft Hospice and Palliative Care Report establishes the foundation for coordinated quality measurement in these two settings with careful thought of the inherent setting challenges. Although quality measures are new to these settings, both settings are an important part of the continuum of care across the lifespan. APTA would suggest the alignment of data definitions for measures in PAC and LTC settings, where possible, in order to better facilitate measurement of outcomes across this continuum of care.</p> <p>As the measures grow in these settings, APTA would advocate for the integration of functional mobility and self care measures in the palliative care setting, recognizing that measures that reflect maintenance goals or the prevention of deterioration will likely be most appropriate in this setting. We believe there remains a great deal of work in further defining and addressing identified gap areas, as well as creating a unified data set in an effort to harmonize measures. We look forward to working with the Measure Applications Partnership to advance these ideas in the future.'</p> |

| Comment Category                      | Commenter Organization                                    | Commenter Name    | Comment   |
|---------------------------------------|---|-------------------|---|
| <b>General Comments on the Report</b> | American Psychiatric Institute for Research and Education | Robert Plovnick   | <p>The American Psychiatric Association is pleased that behavioral health is a valued component of the measure concepts within the Report. It is concerning however, that the most common psychiatric symptom seen in hospice and palliative care settings, and one of the most distressing, is agitation, yet measures focused on this symptom are non-existent. The second most common symptom is anxiety, which is also without performance measures. While there is an indicator for screening depression, literature shows that only 15% of those patients have major depression. There aren't any measures that evaluate the most prevalent psychiatric symptoms within this patient population. These would be important areas to focus future measure development.</p> <p>Further, while the APA is also pleased to see a screening for depression among the endorsed measures (NQF# 0518), please note that without including some sort of plan for a positive screen, this type of measures tends to have limited value.</p> <p>Additionally under the Access to Care section, the Report only lists access to spiritual care but not psychosocial care. Under Family Centered Care bereavement care for the patient and the family should be listed separately, as psychiatric and psychological care is often thought of for the patient, it should be explicit is for both family and patient and through the bereavement period.'</p> |
| <b>General Comments on the Report</b> | America's Health Insurance Plans                          | Carmella Bocchino | <p>'We support the report and feel that the report represents an important step in assessing performance in the area of hospice and palliative care. The terms hospice and palliative care should be clearly defined in the report. While the report represents an excellent first step, the proposed measures apply only to hospice and palliative care programs. A logical next step would be to ensure that patients who receive end of life care in a hospital or SNF have the same level of compassionate care as those enrolled in a hospice and palliative care programs. We would urge the scope of the program to be expanded to encompass all patients receiving end of life care.</p> <p>We also endorse the need for a common data collection and exchange platform. Electronic exchange of information is particularly pertinent as hospice and palliative care often occurs across multiple settings and highlights the need for effective care transitions.'</p>   |
| <b>General Comments on the Report</b> | Highmark, Inc.  | Leslie Boltey     | <p>'MAP report was deemed timely, necessary and well-structured. Of note, internal discussion on this report highlighted that while there are overarching concepts / needs in measurement development for these care programs, there is a missed opportunity to provide education on and clearly define the differences between hospice and palliative care. It is recognized that MAP did list Provider Competency as one of the high-level concepts.'</p>   |

| Comment Category                      | Commenter Organization   | Commenter Name   | Comment  |
|---------------------------------------|--|------------------|--|
| <b>General Comments on the Report</b> | Lister Hill National Center for Biomedical Communications, NLM, NIH, HHS | Clement McDonald | <p>Disclaimer</p> <p>These comments are my own and do not necessarily represent the official position of NIH, NLM, or the Department of Health and Human Services.</p> <p>This document has many insightful comments about the issues related to palliative care and the risks of some hospital measures having perverse consequences on the use of palliative care. These should be distributed broadly to the other MAP developers. The points related to optimizing the use of Palliative care were also very positive. My only complaint about this document was the difficulty in discerning what items are being proposed as actual measures to implement and whether/how they could/would be implemented. Some seemed to be talking about an area of interest but were not couched in a clearly measurable form. At the end, there was an expression of interest in identifying the data elements that would be needed to implement them, but I gather that such an inventory has not been done.'</p>   |
| <b>General Comments on the Report</b> | Lister Hill National Center for Biomedical Communications, NLM, NIH, HHS | Clement McDonald | <p>Disclaimer</p> <p>These comments are my own and do not necessarily represent the official position of NIH, NLM, or the Department of Health and Human Services.</p> <p>A broad concern is the assumption that we should have lots of quality measures in this space just to have them. This is a very private space between patient, and family, and health care providers. It should be kept that way. All issues related to dying in America are highly charged in America. The political reactions have been unpredictable and harsh. (Recall the physician who was criminally charged for providing strong palliative care.) This is not the space to over measure, or to spend energy on detailed data collection and the production of public reports.'</p>   |
| <b>General Comments on the Report</b> | National Association of Social Workers (NASW)                            | Chris Herman     | 'NASW commends the committee on this report. We believe the performance measurement coordination strategy outlined in the report has the potential to help ensure that hospice and palliative care programs provide coordinated services that center on the goals, strengths, needs, and preferences of individuals and families affected by serious or life-limiting illness.'  |
| <b>General Comments on the Report</b> | Pacific Business Group on Health   | Dena Mendelsohn  | The Consumer-Purchaser Disclosure Project (CPDP) appreciates the opportunity to comment on the MAP report on performance measurement for hospice and palliative care. While the MAP PAC/ LTC Workgroup did a tremendous job evaluating and making recommendations on measures for hospice and palliative care, we recognize that there is still much ground to cover in this area, mainly due to the dearth of meaningful measures available to assess quality of care delivered in these setting. This shortfall affects both the quality and cost of that care. As the report states, "Providing palliative care options to individuals improves value by increasing their quality of life according to their goals, effectively coordinating their care, and reducing unwanted and often unnecessary procedures. Evidence also indicates that both hospice and palliative care may increase a patient's longevity." For those reasons, we strongly support any role that the MAP can play to encourage development of measures to fill these gaps.' |

| Comment Category                      | Commenter Organization                              | Commenter Name | Comment   |
|---------------------------------------|---|----------------|---|
| <b>General Comments on the Report</b> | WellPoint   | Lisa Latts     | <p>'We also endorse the need for a common data collection and transmission platform. Electronic exchange of information is particularly pertinent as hospice and palliative care often occurs across multiple settings and highlights the need for effective care transitions, and the MAP delineated data principles to reduce quality measurement burden and facilitate health IT adoption and use.</p> <p>Thank you for the opportunity to comment on this important effort.'</p>  |
| <b>High-Leverage Measure Concepts</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>The National Coalition of Hospice and Palliative Care (NCHPC) agrees with inclusion of all listed measure concepts. We suggest addition of provider self-care, patient and family understanding of illness and prognosis, the interdisciplinary team and caregiver-directed plans.</p> <p>Since there is currently NO regulation or licensing for non-hospice palliative care and voluntary Joint Commission certification for palliative care only began in 2011, we recommend including structural measures, for palliative care. "Qualified health care teams" should be a high priority concept for both palliative care and hospice. Professional social workers (BSW and MSW) are essential to high quality palliative and hospice care. NCHPC supports NASW's further comments on this.</p> <p>The concept "avoiding unwanted treatments" should be applied to palliative care as well as hospice. This concept has even more potential for driving improvement in a palliative care setting than in a hospice setting. It may be helpful to rename this concept "matching care to patient preference."</p> <p>Avoiding or shortening unwanted ICU stays should be specifically included within either "Avoiding unnecessary hospital and ED admissions" or "avoiding unwanted treatments. Solid evidence demonstrates that palliative care interventions decrease length of ICU stays, suggesting it is an appropriate quality target for ongoing intervention.'</p> |
| <b>High-Leverage Measure Concepts</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>AAHPM agrees with inclusion of listed measure concepts and suggests adding: provider self-care, patient and family understanding of illness and prognosis, the components of the palliative care interdisciplinary team and caregiver-directed plans.</p> <p>Unlike hospice, palliative care programs are not licensed or regulated and have no defined structure. Therefore, we propose that measuring "qualified health care teams" including training and certification should be a high priority concept for both palliative care and hospice.</p> <p>The concept "avoiding unwanted treatments" should be applied to palliative care as well as hospice. Matching care with patient preferences is one of the most important ways palliative care teams improve quality of life and add value. It is difficult to define "unnecessary" medical treatments. We suggest that "potentially inappropriate" is a more helpful term and should encompass the patient's condition, prognosis and preferences. Avoiding or shortening inappropriate ICU stays is just as important as "avoiding unnecessary hospital and ED admissions". Solid evidence demonstrates that palliative care interventions decrease length of ICU stays.'</p>  |
| <b>High-Leverage Measure Concepts</b> | American College of Chest Physicians                | Jeff Maitland  | <p>Approve without comments. On behalf of the American College of Chest Physicians (ACCP) the ACCP Quality Improvement Committee (QIC) appreciates the opportunity to comment on this report.</p>   |

| Comment Category                      | Commenter Organization                        | Commenter Name    | Comment   |
|---------------------------------------|---|-------------------|---|
| <b>High-Leverage Measure Concepts</b> | American Hospice Foundation                   | Naomi Naierman    | American Hospice Foundation recommends that the perspective of would-be consumers be considered early in the measure development process. As key end-users, dying patients and families need information to make informed healthcare choices, arguably among the most important decisions that confront so many of us as patients and/or family members. As for measures that are already in their final stage, we suggest that they, too, be tested with consumers to confirm that they are meaningful and usable.'  |
| <b>High-Leverage Measure Concepts</b> | American Nurses Association                   | Maureen Dailey    | <p>The ANA supports the inclusion of all the measure concepts and supports the National Coalition of Hospice and Palliative Care (NCHPC), which includes the Hospice and Palliative Nurses Association (HPNA) comments on measure gaps in the following areas:</p> <p>Provider self-care,<br/> Patient and family understanding of illness/prognosis,<br/> Structural issues, especially the components of IDT team for palliative care, and<br/> Caregiver-directed plans and interventions.</p> <p>The ANA also supports the NCHPC's comments supporting a structural measure for palliative care for the reasons that NCHPC illuminated. High quality team-based palliative care will improve care access to patient-centered care and reduce unwanted futile care, which is often painful and costly in human and dollar costs (e.g., unwanted readmissions, emergence department use, and prolong ICU stays).'</p>   |
| <b>High-Leverage Measure Concepts</b> | America's Health Insurance Plans              | Carmella Bocchino | We support the areas identified as high priority in the report. Six of the seven high priority measure concepts represent the key attributes of excellent hospice and /or palliative care. Avoiding unnecessary hospital and ED admissions are a measure of the effectiveness of the hospice/palliative care program. The use of attributes of highly effective care is the starting point for the development of measures cutting across the silos of care for effective management of patients at the end of life.  |
| <b>High-Leverage Measure Concepts</b> | National Association of Social Workers (NASW) | Chris Herman      | NASW supports the inclusion of the measure concepts listed in the draft report. Similar to the National Coalition for Hospice and Palliative Care, NASW recommends that NQF prioritize structural measures, especially measures addressing the components of palliative care interdisciplinary teams. We assert that "qualified health care teams" are a high priority for both hospice programs and non-hospice palliative care programs. Neither the Conditions of Participation for Medicare- and Medicaid-Certified Hospice Programs nor the Joint Commission's advanced certification for hospital-based palliative care programs requires a bachelor's or master's degree in social work (BSW or MSW). In the absence of such a requirement, the quality of services provided to individuals and families may be compromised. NASW's Standards of Classification specify the BSW as the minimum preparation for professional social work; other bachelor's-level degrees do not prepare individuals for social work practice. Moreover, research supports the value of professionally trained social workers--that is, individuals with BSWs or MSWs--on the hospice team. Thus, NASW asserts that professionally trained social workers are essential to the provision of high-quality hospice and non-hospice palliative care, and that measures are needed to monitor the quality of services provided by individuals providing social work or social services in those settings.' |

| Comment Category                                     | Commenter Organization                              | Commenter Name  | Comment  |
|--|---|-----------------|--|
| <b>High-Leverage Measure Concepts</b>                | Pacific Business Group on Health                    | Dena Mendelsohn | ‘The Consumer-Purchaser Disclosure Project (CPDP) supports the high leverage measure concepts listed in this report. We are particularly pleased to see Experience of Care, Care Planning, Implementing Patient/Family/Caregiver Goals, and Avoiding Unnecessary Hospital and ED Admissions highly prioritized. We are, however, disappointed to see certain measures are specified for use in either hospice or palliative care settings. These measures, such as Timeliness/responsiveness of care, Sharing Medical Records Across All Providers, and Access to Hospice/Palliative Care are equally applicable to both settings of care. We suggest that the Workgroup recommend, and the final report reflect, the notion that measure developers should pursue harmonization of these measures in a timely manner.’  |
| <b>High-Leverage Measure Concepts</b>                | WellPoint   | Lisa Latts      | <p>We agree with the MAP that the following measure concepts are a high priority:</p> <ul style="list-style-type: none"> <li>Access to hospice and palliative care</li> <li>Access to the healthcare team on a 24-hour basis</li> <li>Comprehensive assessment (bundled measure)</li> <li>Patient education and support</li> <li>Timeliness/responsiveness of care</li> </ul> <p>We would encourage measure developers to consider how to ensure that measures of access specifically address each of the settings for palliative care and hospice as patients and their families may prefer to receive services in different settings.</p>  |
| <b>Application and Refining of Existing Measures</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu       | <p>NCHPC notes the urgent need for more outcome measures, but recognizes those in development are not yet mature enough for NQF approval or public reporting.</p> <p>We recommend developing a set of high-yield symptom measures (e.g. pain, dyspnea, depression, nausea, fatigue), including both assessment and management. These symptom measures should be applicable across all settings and diagnoses. We recommend application of CARE across all settings. Further, work is needed to assure comparability of site-specific tools such as FEHC and BFS to assure continued meaningful comparisons across sites of care. Finally, development of measures of psychosocial and spiritual care should be a top priority. We support NASW’s further detailed comments on psychosocial concepts and measures.</p> <p>While O215, “Proportion not admitted to hospice”, can measure access for a population, it cannot be meaningfully applied to an individual hospice. In areas with multiple hospice providers, it is impossible for an individual provider to determine an appropriate denominator. We therefore recommend AGAINST its inclusion in the Medicare required quality measures for hospices.</p> <p>Additional measures should be indicated as appropriate for the LTC setting. In particular, O326, “Advance care plan”; is a key tactic for avoiding inappropriate ED, hospital and ICU admissions.</p> |
| <b>Application and Refining of Existing Measures</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu       | <p>Additional measures should be indicated as appropriate for the LTC setting. In particular, O326, “Advance care plan” is a key tactic for avoiding inappropriate ED, hospital and ICU admissions.</p>  |

| Comment Category                                     | Commenter Organization               | Commenter Name | Comment  |
|--|--------------------------------------|----------------|--|
| <b>Application and Refining of Existing Measures</b> | American College of Chest Physicians | Jeff Maitland  | Approve without comments. On behalf of the American College of Chest Physicians (ACCP) the ACCP Quality Improvement Committee (QIC) appreciates the opportunity to comment on this report.   |
| <b>Application and Refining of Existing Measures</b> | American Geriatrics Society          | Susan Sherman  | <p>'We believe that there is a potential gap in the measurement of hospice care, as this is limited based on the lack of engagement of primary and specialty care. This is often translated into late or no referrals, and no advanced directives or goals of care. Inevitably, this lack of engagement leads to a fairly big challenge for hospice to be part of the continuum.</p> <p>Another gap we wanted to bring attention to pertains to how palliative care fits into the continuum. With the exception of inpatient care, there is no vehicle for payment for home based palliative care.'</p>  |
| <b>Application and Refining of Existing Measures</b> | American Hospice Foundation          | Naomi Naierman | As an organization that looks out for hospice consumers, American Hospice Foundation notes one important gap that is not addressed, yet frequently comes up in calls we receive from family members of hospice patients. Hospices need formal processes for patients and families to communicate and escalate concerns with care. When family members feel their loved one is not getting appropriate care, they experience anger, confusion and fear. Often when this situation occurs, it is because the hospice has not adequately communicated the rationale for its approach. Regardless, however, of whether the problem is inappropriate care or failure to communicate adequately, the result is stress for patients and caregivers that could be avoided if they knew how to escalate their concerns when it is not immediately and sufficiently addressed by the direct care team. Learning after the death through a survey that caregivers were upset about one or more aspects of hospice care is too late. A system needs to be in place for caregivers to register complaints about problems before the death, so they can comfortably feel everything possible was done. Therefore, we recommend the development of a measure that assesses the presence of an adequate grievance resolution system, and communication of the existence of the process to patients and families upon their admission.' |
| <b>Application and Refining of Existing Measures</b> | American Nurses Association          | Maureen Dailey | <p>The ANA supports the NCHPC's comments on measure maturity, development issues, and gaps. In particular, the ANA supports NCHPC's support of long term care (LTC) measures, such as advanced care planning. The NPP's Readmission Task Force has highlighted the need for palliative care/end of life advance care planning and team-based education, training, and support.</p> <p>The ANA also supports NCHPC's call for high impact symptom outcomes measures reported by the team, given the limited number of available, NQF-endorsed patient-reported measures. The NPHPC call for these measures to be cross cutting (e.g., across settings, team-members, and multiple chronic conditions beyond cancer) is appropriate. The ANA supports the NCHPC's suggested next steps for measure development, including filling measure gaps in the psychosocial and spiritual components of care.'</p>  |

| Comment Category                                     | Commenter Organization                        | Commenter Name    | Comment  |
|--|---|-------------------|--|
| <b>Application and Refining of Existing Measures</b> | America's Health Insurance Plans              | Carmella Bocchino | 'This section clearly demonstrates the gap in measures that define the attributes of hospice and palliative care. The process used to re-assess the gaps in the measures, comparing them against a set of standards, represents the right approach. Additionally we strongly encourage the MAP to consider the proposed measures across all palliative care and hospice settings listed in table 2 as appropriate. Consistency in measurement across settings is essential to be able to compare patient and family experiences and quality of life in the different care settings where palliative care may be provided. The following measures should be applicable across all hospice and palliative care settings: 0216, 0518, 1634, 1637, 1638, 1639, 1617, 0179, 1894, 1898, 1623, 1632, 1641, 0648, 0213, 0214, 0211, 0212, 0171, and 0173.'  |
| <b>Application and Refining of Existing Measures</b> | Eisai, Inc.                                   | Charles Hampsey   | Eisai agrees with MAP that there is "the possibility of undesirable consequences from applying certain measures". 0210 (Proportion receiving chemotherapy in the last 14 days of life) is intended to measure over-treatment at the end of life. Yet, the measure does not tell us when patients were placed on chemotherapy (was it 6 months before death, was it 12 months?). Therefore, 0210 could reduce access to cancer care earlier in the treatment process, especially if tied to performance. We also do not know the treatment goal (e.g. palliative chemotherapy, extended survival). 0210 paints the proportion receiving chemotherapy with the same broad brush of having received over-treatment. Eisai disagrees that this measure is ready for immediate application.<br><br>"Plan of Care for Pain" and "Pain Intensity Quantified" (0383 and 0384) are designated by CMS for registry reporting. These measures target patients receiving IV chemotherapy or radiation therapy. If a patient is prescribed oral chemotherapy they are excluded as the measure requires a CPT code for IV drug administration. This year, the steward, ASCO, is developing an EHR reporting option for 0383 and 0384. Registry and EHR reporting allow for oral and IV chemotherapy data to be collected. Eisai believes the steward should broaden 0383 and 0384 to include all treatment modalities before the measures are expanded to other programs.' |
| <b>Application and Refining of Existing Measures</b> | Highmark, Inc.                                | Leslie Boltey     | 'The selection of high-leverage measure concepts , especially Access to Hospice and Palliative Care and Appropriate Levels of Services, is strongly supported. The data reflected within the report concerning the average length of stay, provokes supposition that unwanted and ineffective care processes may be incurred without appropriate risk/benefit.'  |
| <b>Application and Refining of Existing Measures</b> | National Association of Social Workers (NASW) | Chris Herman      | NASW encourages any measurement of patient depression to take into account that social and somatic symptoms typically associated with depression (such as social isolation, reduced appetite, weight loss, or increased sleeping) and included in standardized screening instruments may not be indicative of depression for individuals at the end of life. Furthermore, we assert that psychological and psychiatric measures are important not only for the reasons noted in the report but also, and equally importantly, to ensure that patients and families receive needed support. We also echo the National Coalition for Hospice and Palliative Care's call for outcome measures and patient-reported measures.'   |



| Comment Category                                     | Commenter Organization           | Commenter Name  | Comment   |
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| <b>Application and Refining of Existing Measures</b> | Pacific Business Group on Health | Dena Mendelsohn | <p>In addition to looking at the tangential impact of certain measures, we support the MAP's encouragement of development of measures "so they are applicable across multiple hospice and palliative care settings." As discussed under High-Leverage Measure Concepts, CPDP is disappointed to see certain measures specified for either hospice or palliative care settings, but not both. For example, timeliness/responsiveness of care, shared medical records across providers, and access to care are a mutual concern among patients in both settings.</p> <p>Perhaps most important of CPDP's three areas of concern in this report is the need for prioritization of patient-centered and outcomes based measures. As discussed earlier in these comments, hospice and palliative care settings have not received the same attention in the measurement arena as have other areas of care. Further, the measures that do exist tend to focus on problems in the provision of health care rather than identifying quality care through measuring outcomes. That NQF has endorsed patient-centered and outcomes-based measures in other areas is evidence that such measurement schemes are viable. In addition to those measures identified by the report for highest priority, the following should be highly prioritized: (1) implementing patient/family/caregiver goals, (2) shared decision making, (3) appropriate level of services, and (4) cost of care.'</p> |
| <b>Application and Refining of Existing Measures</b> | Pacific Business Group on Health | Dena Mendelsohn | <p>Public reporting of performance measures for hospice and palliative care lingers behind the reporting available for other health care providers. However, this area of care is important to patients and their families; thus, CPDP applauds the MAP for pursuing improvements in this area of care. Indeed, there is much room for improvement.</p> <p>The CPDP agrees with this Report's assertion that there is a possibility of unintended adverse consequences when implementing certain measures. As with all areas of performance measurement, efforts should be made to ensure that there is minimal or no negative collateral impact due to implemented measures. At the same time, we must recognize that in some cases, the aggregate value of some measures can be viewed as outweighing the risk. For example, we understand why the measure Percentage of Residents Who Lose Too Much Weight is controversial, due to the risk that caregivers may force feed patients who naturally lose weight as a result of their condition (particularly a concern with dementia patients). However, in the broader scheme, consumers are concerned about care at the nursing home level, and food consumption and access is an important element of that care. In the end, we strongly support the development and implementation of measures that can account for, and exclude when necessary, those patients for whom the measure may not apply.'</p>                  |
| <b>Application and Refining of Existing Measures</b> | Vitas Healthcare Corporation     | Karen Mikula    | <p>'It is crucial to consider the burden to hospice providers when selecting measures for proposal. Measures which involve harvesting data from medical records are especially burdensome; they can be very time consuming and resource depleting. We also recommend gradual introduction of measures rather than immediate application of all available measures. Implementing a measure into the existing processes and structure of a hospice requires a significant amount of time and coordination if implementation is to be successful. In order for the hospice Quality Reporting effort to be a success, measure introduction must be done in a manner which will allow hospices to integrate the measures successfully and see the benefits rather than struggling with the burden.'</p>  |

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| <b>Application and Refining of Existing Measures</b>  | WellPoint   | Lisa Latts     | <p>We would strongly encourage the NQF Measures Application Partnership to consider implementing the proposed Measures for Application or Refinement in Hospice and Palliative Care (Table 2) across all palliative care and hospice settings unless specifically not applicable to that setting. Consistency in measurement across settings is essential to be able to compare patient and family experiences and quality of care in myriad of different settings where palliative care may be appropriately delivered.</p> <p>Specific Comments on individual measures:</p> <p>O215 Proportion not admitted to hospice: This measure appears to be proposed for patients enrolled in the Medicare Hospice Program. However, this is a measure of whether or not patients were appropriately referred to and enrolled in hospice. Therefore, this measure would apply to all patients in palliative care programs; however, patients already enrolled in hospice should not be eligible.</p> <p>O216 Proportion admitted to hospice for less than 3 days: This measure is applicable to all palliative care settings, not just the hospital setting.</p> <p>O518 Depression assessment conducted: This measure is applicable to all palliative care settings.</p> <p>Other measures that are applicable to all palliative care settings are 1894, 1898, and 1623.</p> <p>The following measures are also applicable to all palliative care and hospice settings.</p> <p>1634, 1637, 1638, 1639, 1617, 0179, 1632, 1641, 0648, 0213, 0214, 0211, 0212, 0171, 0173'</p> |
| <b>Path Forward for Improving Measure Application</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>The critical barrier to measuring non-hospice palliative care quality is the lack of a consistent way to identify palliative care patients. Current v-codes for palliative care are applied inconsistently. We need standardized data elements that differentiate patients receiving specialty palliative care from those receiving palliative care from other providers such as oncologists. A denominator of all patients potentially appropriate for palliative care is also needed.</p> <p>We heartily concur that “a performance measurement strategy for hospice care provides a unique opportunity to pave the way for positive changes for all healthcare.” However, we hope that this report will articulate a clearer strategy. We urge the following steps: first implement measurement of high yield symptoms set across all settings, second expand pt/family surveys such as CARE to all settings and assure comparability across settings of FEHC and BFS, and finally, develop measures of the psychosocial and spiritual aspects of care.</p> <p>For the immediate need of publicly reportable measures for the Medicare Hospice program, we recommend starting with the FEHC and a set of symptom measures that include both assessment and timely management.</p> <p>Finally, we urge attention to HOW information is publicly reported. For quality information to be useful to consumers, it must be reported in formats built on current evidence of what consumers find meaningful and understandable.</p>                                   |

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| <b>Path Forward for Improving Measure Application</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>For the Medicare Hospice Program's first publicly reportable measures, we recommend the FEHC and high-yield symptom measures including both assessment and timely management.</p> <p>Measures should be carefully evaluated for evidence that they improve care and drive exploration of the patient's view of potential benefit, risk and burden.</p> <p>Finally, we urge attention to HOW information is publicly reported. For quality information to be useful to consumers, it must be reported in formats built on current evidence of what consumers find meaningful and understandable.'</p>   |
| <b>Path Forward for Improving Measure Application</b> | American Academy of Hospice and Palliative Medicine | Dale Lupu      | <p>Current v-codes for palliative care are applied inconsistently. We need standardized data elements that would differentiate patients receiving specialty palliative care from those receiving palliative care from other providers such as oncologists. A denominator of all patients potentially appropriate for palliative care is also needed.</p> <p>We agree that "a performance measurement strategy for hospice care provides a unique opportunity to pave the way for positive changes for all health care, leading to a better coordinated, team-based approach emphasizing patients' values and preferences." However, we urge the articulation of a clearer strategy. First, implement measures of high-yield symptoms across all settings. Second, expand patient/family surveys such as CARE to all settings and maintain cross-site compatibility of site-specific surveys such as FEHC. Finally, develop measures of the psychosocial aspects of care.'</p> |
| <b>Path Forward for Improving Measure Application</b> | American College of Chest Physicians                | Jeff Maitland  | Approve without comments. On behalf of the American College of Chest Physicians (ACCP) the ACCP Quality Improvement Committee (QIC) appreciates the opportunity to comment on this report.  |
| <b>Path Forward for Improving Measure Application</b> | American Geriatrics Society                         | Susan Sherman  | Overall, we support the report's focus on the critical importance of avoiding hospital and emergency department use when possible. Items such as measuring chemotherapy in the last two weeks of life, death in the intensive care unit, and measuring how many hospitalizations before death, are topics that we agree, are important to measure.'   |
| <b>Path Forward for Improving Measure Application</b> | American Hospice Foundation                         | Naomi Naierman | 'To ensure that the measures selected for public reporting are readily understandable and easily accessible, more research is needed on a design and dissemination plan that is helpful to folks who understand hospice, as well as those who are unfamiliar with it. For the latter group, it is essential that a hospice public report includes an educational module that is cognitively tested with a wide variety of consumers. An example of such a module is shown in the model hospice report card developed by American Hospice Foundation. ( <a href="http://ahfconsumerdemo.deyta.com/">http://ahfconsumerdemo.deyta.com/</a> )'   |
| <b>Path Forward for Improving Measure Application</b> | American Nurses Association                         | Maureen Dailey | The ANA supports NCHPC's comments. Specifically, ANA agrees there needs to be a consistent way to identify current and potential palliative care patients through a core set of cross-cutting standardized data elements for use across teams, care settings etc. The ANA agrees with NCHPC's comments that a clear strategy is needed to implement measurement of high yield symptoms set across all settings and expansion of pt/family surveys.'   |

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| <b>Path Forward for Improving Measure Application</b> | America's Health Insurance Plans              | Carmella Bocchino | The attributes of a highly effective hospice/palliative care program (the High-leverage measure concepts) were based upon consensus. These attributes should be tested by analyzing performance of existing hospice and palliative care programs to ascertain whether these are truly the best attributes and ones universally found among excellent programs. Based on such analysis the High-Leverage Measure Concepts may need to be modified prior to a call for measures that describe these attributes.   |
| <b>Path Forward for Improving Measure Application</b> | National Association of Social Workers (NASW) | Chris Herman      | NASW strongly recommends solicitation and development of measures addressing the psychosocial aspects of palliative and hospice care. In both hospice and non-hospice palliative care programs, measures addressing the following topics are needed: patient and caregiver education and support, culturally and linguistically appropriate care, ethical and legal aspects of care, grief and bereavement care planning, social care planning, timely communication of patients' goals across all providers, implementing patient and family goals, shared decision making, and existential concerns.' |
| <b>Path Forward for Improving Measure Application</b> | Pacific Business Group on Health              | Dena Mendelsohn   | The Consumer-Purchaser Disclosure Project (CPDP) supports the report's recommendation to create "families of measures that can be applied as core measure sets across programs, settings, level of analysis, and populations to ensure a patient-focused, cross-cutting assessment of quality." Uniform measures across the final stages of care provide a meaningful foundation from which to develop other more care-specific measurement tools.'   |

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