Performance Measurement Coordination Strategy for Hospice and Palliative Care

Executive Summary

The use of hospice and palliative care services in the U.S. is on the rise, with more than double the number of people now in hospice programs than there were a decade ago. Hospice and palliative services, through their holistic and patient- and family-centered approach, can offer a form of care that is more responsive to patient's goals and preferences and is also less costly. At the same time, patients run the risk of being exposed to fragmented and uncoordinated care, given the multiple settings and providers involved.

New in law, a provision that begins in 2014 will require hospice programs to submit quality data to the federal government. This requirement, 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 strategy, or roadmap, could ensure that measurement 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.

To develop this strategy, the Department of Health and Human Services (HHS) turned to the Measure Applications Partnership (MAP). 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.

Improving hospice and palliative care provides an opportunity to advance two significant priorities of the National Quality Strategy – patient- and family-centered care and care coordination. Effectively delivered, hospice and palliative care move the healthcare system toward a different model where the emotional, spiritual, and psychosocial needs of patients are just as important as their physical needs. Hospice and palliative care are also uniquely team-based, requiring a group of providers, health care professionals, and caregivers to coordinate care and family involvement across multiple settings of care. But to make rapid gains, much work remains to be done to evolve the measurement foundation so that it promotes effective improvement.

To move in that direction, this report identifies 28 measure concepts for hospice and palliative care that focus on patients' and families' needs and preferences, measured across settings of care and diverse providers. These concepts address the following:

- **Access and Availability of Services,** recognizing that there is a need for greater awareness of the option of hospice and palliative care services, and also assessing the timeliness of care once a patient has decided to receive hospice or palliative care
- **Patient- and Family- Centered Care,** which comprises education and support for both patients and caregivers so that they understand the care being provided; comprehensive assessments including the spiritual, physical, and psychological aspects of care; and the patient's and family's experiences of care
- **Goals and Care Planning**, includes establishing patient and family goals with regard to the care of the patient and periodically reviewing to update care plans
- **Care Coordination** should assess if patients' goals, care plans, and medical records are communicated throughout the care team and across health care settings

- **Provider Competency** ensures that the patient 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** assesses whether patients are avoiding unwanted trips to the hospital and unwanted medical procedures

The report identifies more than a dozen existing measures that are ready for immediate application in the Medicare Hospice Quality Measurement Program, as well as measures that can be applied to palliative care settings. It also notes significant measure gaps and suggestions for modifying existing measures to expand them to broader settings and populations.

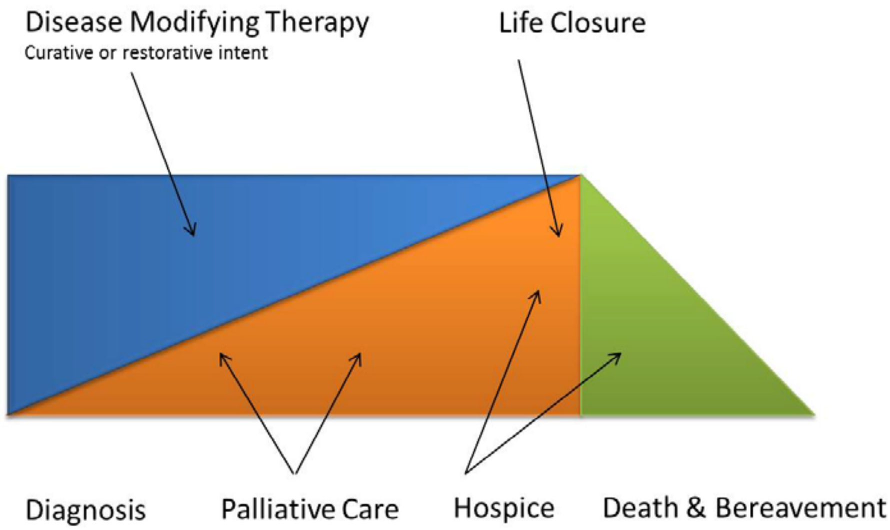
MAP acknowledges the many challenges in filling the measurement gaps in this area, and in advancing a coordinated measurement strategy. Health information technology-enabled data collection and transmission have the potential to promote both goals. MAP urges the application of these tools to palliative and hospice care, particularly to ensure smooth transitions among care settings and accelerate measurement of patients' experience of care.

MAP views the new quality measure reporting requirements for hospice care as a valuable opportunity to improve care coordination across settings, to increase access to both hospice and palliative care for all patients, and to shine a bright light on patient- and family- centered care as the ideal model for all healthcare.

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, psychosocial, 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.[i] Palliative care may be provided well in advance of the final stages of an illness and seeks to optimize quality of life by addressing physical, intellectual, emotional, social, and spiritual needs throughout the illness trajectory and by facilitating patient autonomy, choice, and access to information.[ii] Palliative care can be provided within and beyond hospice programs. 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 not survive past six months and the patient ceases curative therapies.

Figure 1. Hospice and Palliative Care Along the Continuum of Care



Enrollment in hospice programs has risen by over 50% in the last decade,[iii] 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.[iv] 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 value by increasing their quality of life according to their goals, effectively coordinating their care, and reducing unwanted and often unnecessary procedures.[v]Evidence also indicates that both hospice and palliative care may increase a patient's longevity.[vi]

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% of the time, but also is in an assisted living facility for 11% of the time, and a nursing home for 17% of the time.[vii] 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.[viii]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 MAP's 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 measure concepts 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 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. The MAP PAC/LTC Workgroup is a 22-member, multi-stakeholder group (see Appendix B for the workgroup roster, Appendix C for the Coordinating Committee roster). The workgroup held one in-person meeting and one web meeting to finalize the measure concepts and 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 hospice meeting 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.[ix]
- *National Voluntary Consensus Standards: Palliative Care and End-of-Life Care*, which includes the results of the evaluation of 22 measures submitted for endorsement under NQF's Consensus Development Process.[x]
- *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.[xi]
- *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.[xii] [xiii]

MAP PAC/LTC Workgroup members developed priority measure concepts 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 measure concepts of importance to hospice and palliative care (see Table 1). Establishing these measure concepts 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 immediate application and measures for 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 measure concepts for hospice and palliative care. Moreover, measure identification 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 Measure Concepts

In considering the continuum of hospice and palliative care, MAP established high-leverage measure concepts, 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. 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. Additionally, while regional prevalence of hospice care programs is comparable, regional variation in utilization of hospice care persists.[xiv] 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 earlier in their 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. Finally, regulations may inadvertently impact access to hospice care; patients in nursing homes often need to obtain an individual waiver in order to elect hospice care.[xv] 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, since 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 uniquely 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.

MAP identified 28 measure concepts that are important for hospice and palliative care. These measure concepts represent areas that address the need to provide access to affordable palliative and hospice services; the person- and family-centered nature of care, which focus 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, and psychological well-being. Of the 28 measure concepts, MAP prioritized seven for both hospice and palliative care, three specific to hospice care, and three specific to palliative care. The three priority measure concepts specific to hospice care reflect patients' needs for increased access and communication; the three priority measure concepts specific to palliative care reflect patients' needs for education and care coordination. The measure concepts are not mutually exclusive, and some of the lower-rated concepts may be encompassed within the higher-rated concepts (e.g., care planning could encompass shared decision making).

Highly Prioritized Measure Concepts for Both Hospice and Palliative Care

Experience of care is essential for understanding whether care was timely, coordinated, and met patient and family goals. Specifically applicable 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 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 as it has the largest evidence base and helps avoid unwanted treatments and hospital/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, as patients are not imminently dying so their goals may change over time.

Implementing patient/family/caregiver goals occurs once the care plan has been established. It is imperative that there is a process 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 that would potentially lead to reduced admissions and readmissions.

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 as behavioral changes significantly add to burden and can lead to an unstable care plan, hospital admissions, and crisis interventions.

Highly Prioritized Measure Concepts for Hospice Care

Timeliness/responsiveness of care is vital to providing optimal hospice care as 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 measure concepts such as assessments and care planning.

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

Avoiding unwanted treatments, when measured, serves as a proxy for appropriate levels of communication and care planning in hospice programs. Unwanted treatments also include unnecessary hospital/ED admissions and readmissions.

Highly Prioritized Measure Concepts 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 reduces 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 patients make more informed decisions regarding hospice care.

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

Table 1. Medicare Hospice Program and Palliative Care Measurement Concepts

High-Leverage Measure Concepts	High Priority Concept	
	Medicare Hospice Program	Palliative Care
Access/Availability of Services		
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	✓	
Patient- and Family-Centered Care		
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		

High-Leverage Measure Concepts	High Priority Concept	
	Medicare Hospice Program	Palliative 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		
Goals and Care Planning		
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		
Care Coordination		
Sharing medical records (including advance directives) across all providers		✓
Timely communication of patients' goals across all providers		
Provider Competency		
Provider education		
Qualified healthcare teams		
Appropriateness/Affordable Care		
Appropriate level of services		
Avoiding unnecessary hospital and ED admissions	✓	✓
Avoiding unwanted treatments	✓	
Cost of care		

Applying and Refining Existing Measures

To begin to address the highly prioritized measure concepts, MAP identified NQF-endorsed measures that could potentially be used to 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 as 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. MAP recognizes that the field of hospice care quality measurement is still new and there is a lack of 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 suggests a phased approach to measurement for hospice and palliative care, beginning with the existing measures, many of which are clinically focused, and phasing in cross-cutting measures over time. Some existing measures should be explored for expansion to include broader settings and populations. For example, some existing cancer care measures should be specified and tested for broader application. MAP also recognizes that there are certain areas of holistic, team-based care (e.g., spiritual counseling, shared decision making) that lack sufficient evidence.[xvi] 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 measures that are ready for immediate application to the Medicare Hospice Quality Measurement Program or to palliative care. Of the two measures already finalized for the Hospice Program, one is NQF-endorsed, Comfortable Dying (NQF #0209), and included in the table below (marked as "Finalized"). A second finalized measure, Hospice Administers a Quality Assessment and Performance Improvement [QAPI] Program Containing at Least Three Indicators Related to Patient Care, is not NQF-endorsed and therefore not reflected in the table. An additional six measures were recommended by MAP in its pre-rulemaking report as additions to the Hospice Program (noted in the table as "MAP supported in pre-rulemaking"). The remaining measures in the table are marked by an "X" as ready for application for either hospice or a particular palliative care setting. MAP encourages additional development and testing of these measures so that they are applicable 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 Measure Concepts/ Measures	Medicare Hospice Program	Palliative Care				Additional Considerations
		Hospital	Clinician Office Setting	PAC/LTC Settings (facilities)	Home	
Access to palliative care						No available measures
Access to hospice care						
0215 Proportion not admitted to hospice	X					Explore expanding beyond cancer population
0216 Proportion admitted to hospice for less than 3 days		X				Explore expanding beyond cancer population
Access to the healthcare team on a 24-hour basis						No available measures
Timeliness/responsiveness of care						No available measures
Availability of spiritual care services						No available measures
Comprehensive assessment—including physical, psychological, spiritual, and social aspects of care						No available measures
Psychological and psychiatric aspects of care—managing anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms						
0518 Depression assessment conducted					X	Explore application to hospice and palliative care patient populations
Spiritual, religious, and existential aspects of care—assessing concerns						
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					
Physical aspects of care—treating pain, dyspnea, constipation, and other symptoms using standardized scale						
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 –	MAP					

High-Leverage Measure Concepts/ Measures	Medicare Hospice Program	Palliative Care				Additional Considerations
		Hospital	Clinician Office Setting	PAC/LTC Settings (facilities)	Home	
pain assessment (paired with 1634)	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 beyond cancer population
Care of the imminently dying patient						No available measures
Culturally and linguistically appropriate care						
1894 Cross-cultural communication domain of the Communication Climate Assessment Toolkit			X			
1898 Health literacy domain of Communication Climate Assessment Toolkit			X			
Patient education and support						No available measures
Caregiver education and support						No available measures
Experience of care						
0208 Family Evaluation of Hospice Care	MAP supported in pre-rulemaking					Explore development of an aligned measure for palliative care that also incorporates patient evaluation of care

High-Leverage Measure Concepts/ Measures	Medicare Hospice Program	Palliative Care				Additional Considerations
		Hospital	Clinician Office Setting	PAC/LTC Settings (facilities)	Home	
1623 Bereaved Family Survey	X			X		*Note*: Measure developed for VA healthcare system
1632 CARE - Consumer Assessments and Reports of End of Life	X	X		X	X	
Care planning—establishing and periodically reviewing patient/family/caregiver goals						
0383 Oncology: plan of care for pain–medical oncology and radiation oncology (paired with 0384)			X			Explore expanding beyond cancer population
1626 Patients admitted to ICU who have care preferences documented		X				
1641 Hospice and palliative care – treatment preferences	X					
Implementing patient/family/caregiver goals						No available measures
Shared decision making						No available measures
Grief and bereavement care planning						No available measures
Social care planning—addressing social, practical, and legal needs of patient and caregivers						No available measures
Ethical and legal aspects of care—including advance directives and surrogate decision makers						
0326 Advance care plan		X				Explore expanding beyond older adults
Timely communication of patients' goals across all providers						
0097 Medication reconciliation			X			Explore expanding beyond older adults
0648 Timely transition of transmission record (inpatient discharges to home/self-care, or any other site of care)			X			
Sharing medical records (including advance directives) across all providers						No available measures
Provider education						No available measures
Qualified healthcare teams						No available measures
Appropriate level of services						
0213 (under review) Proportion admitted to the ICU in the last 30 days of life		X				Explore expanding beyond cancer population
0214 (under review) Proportion dying from cancer in an acute care		X				Explore expanding beyond cancer

High-Leverage Measure Concepts/ Measures	Medicare Hospice Program	Palliative Care				Additional Considerations
		Hospital	Clinician Office Setting	PAC/LTC Settings (facilities)	Home	
setting						population
Avoiding unwanted treatments						
0210 (under review) Proportion receiving chemotherapy in the last 14 days of life		X				Explore expanding beyond cancer population
1625 Hospitalized patients who die an expected death with an ICD that has been deactivated		X				
Avoiding hospital and ED admissions						
0211 (under review) Proportion with more than one emergency room visit in the last days of life		X				Explore expanding beyond cancer population
0212 (under review) Proportion with more than one hospitalization in the last 30 days of life		X				Explore expanding beyond cancer population
0171 Acute care hospitalization (risk-adjusted)					X	
0173 Emergency department use without hospitalization					X	
Cost of care						No available measures

MAP was unable to identify available measures for several of the highly prioritized measure concepts (noted in Table 2 as "No available 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

To achieve a comprehensive core set of hospice and palliative care measures, MAP encourages immediate application of available measures, further refinement of measures that can be expanded to cross populations and settings, and continued testing and development to fill the highest-priority measure gaps.

Pathway for Improving Measure Application for Hospice and Palliative Care

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

This performance measurement coordination strategy identifies key measure concepts and available measures for hospice and palliative care. Many of these concepts align with the measurement priorities and measure concepts 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

The need for a common data collection and transmission platform and 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. MAP has previously delineated data principles that would reduce quality measurement burden and facilitate health IT 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 incorporating best practices for care transitions.

Addressing Measure Gaps

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 families of measures that can be applied as core measure sets across programs, settings, levels of analysis, and populations to ensure a patient-focused, cross-cutting assessment of quality. As de novo measure development and modification of existing measures for broader application occur in these areas, feedback loops need to be incorporated so measurement efforts can bolster the evidence base and to monitor for undesirable consequences of measurement. While 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.

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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.[1]

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.[2] 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.

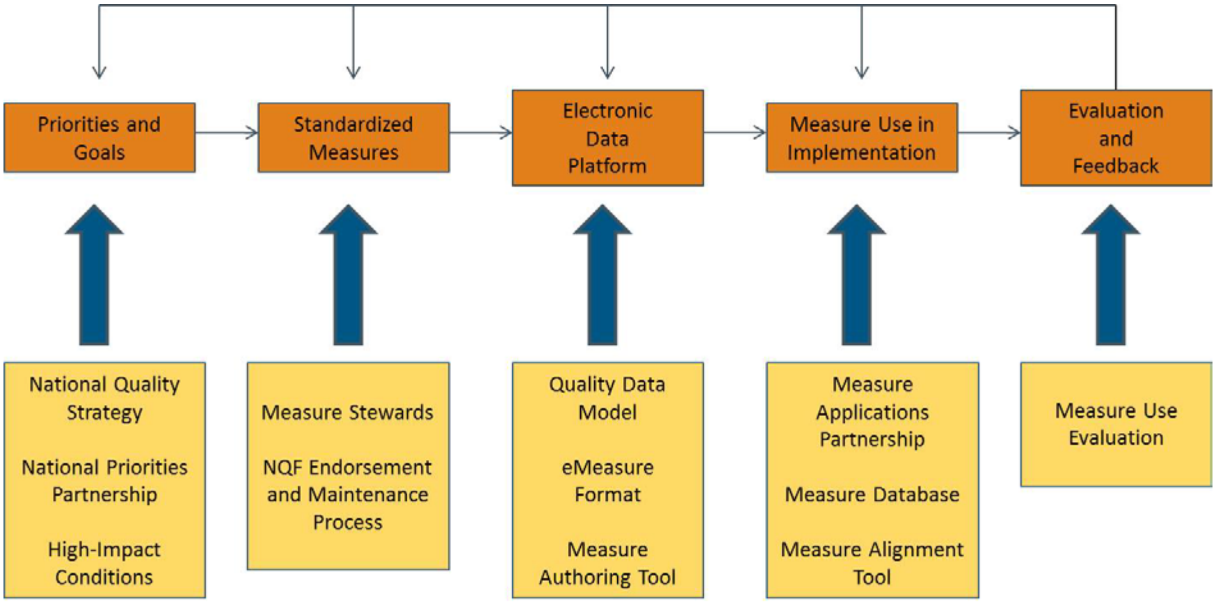
Coordination with Other Quality Efforts

MAP's 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), a multi-stakeholder group convened by NQF to provide input to HHS on the NQS, by identifying priorities, goals, and global measures of progress.[3] Another NQF-convened group, the Measure Prioritization Advisory Committee, has defined high-impact conditions for the Medicare and child health populations.[4] 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.

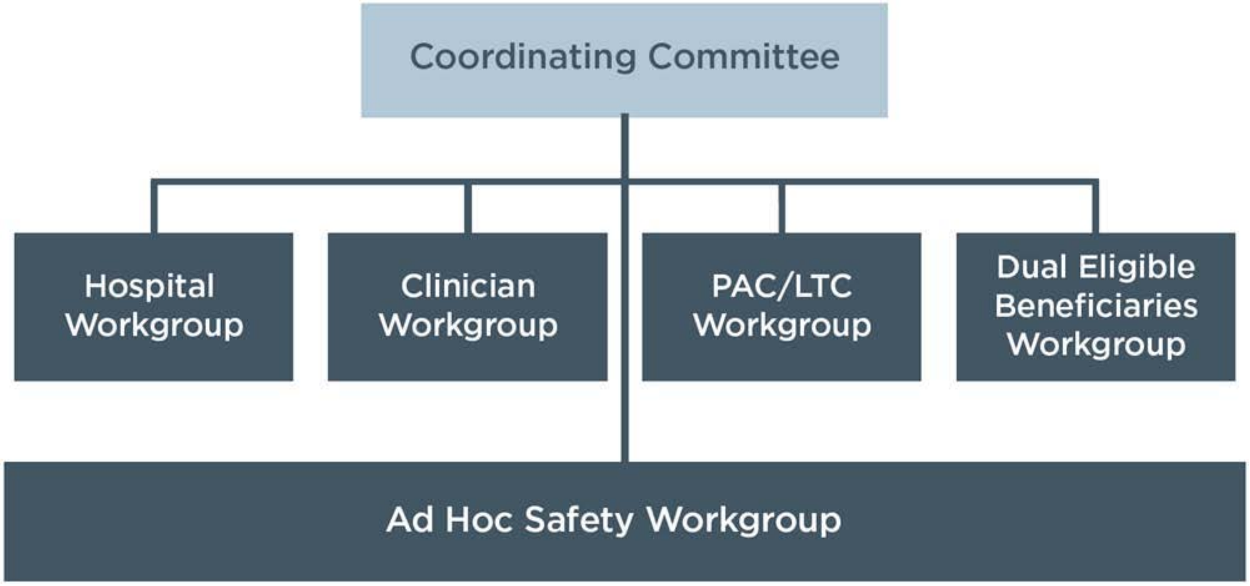
Alignment around environmental drivers, such as public reporting and performance-based payment, is MAP's role in the quality measurement enterprise. By considering and recommending measures for use in specific applications, MAP will facilitate the alignment of public- and private-sector programs and 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.[5,6] 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 commenting 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 Patient-Focused Episodes of Care framework,[7] the HHS Partnership for Patients safety initiative,[8] the HHS Prevention and Health Promotion Strategy,[9] the HHS Disparities Strategy,[10] and the HHS Multiple Chronic Conditions Measurement Framework.[11] Additionally, the MAP Coordinating Committee has developed measure selection criteria to help guide MAP decision making.

Timeline and Deliverables

MAP's initial work included performance measurement coordination strategies 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 information technology (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, three coordination strategies were issued. The report on coordinating readmissions and healthcare-acquired conditions focused on alignment of measurement, data collection, and other efforts to address these safety issues across public and private payers.[12] The report on coordinating clinician performance measurement identified 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.[13] An interim report on performance measurement for dual eligible beneficiaries offered a strategic approach that includes a vision, guiding principles, characteristics of high-need subgroups, and high-leverage opportunities for improvement, all of which will inform the next phase of work to identify specific measures most relevant to improving the quality of care for dual eligible beneficiaries.[14]

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. 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.

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Appendix B

Measure Applications Partnership (MAP)

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

Measure Applications Partnership (MAP)

Roster for the MAP Coordinating Committee

Co-Chairs (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 (non-voting, ex officio)	Representatives
Agency for Healthcare Research and Quality (AHRQ)	Nancy Wilson, MD, MPH
Centers for Disease Control and Prevention (CDC)	Chesley Richards, MD, MPH
Centers for Medicare & Medicaid Services (CMS)	Patrick Conway, MD MSc
Health Resources and Services Administration (HRSA)	Ahmed Calvo, MD, MPH
Office of Personnel Management/FEHBP (OPM)	John O’Brien
Office of the National Coordinator for HIT (ONC)	Kevin Larsen, MD

Accreditation/Certification Liaisons (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	✓	✓	✓	✓